Issues Paper May 2010

Page 3:
First dot point: ‘**provides long-term essential care and support’**: pay support workers more than cleaners; and supermarket shelf fillers, for a start. Look after support workers; if they’re only getting a few hours here and there; naturally they need to move to an employment sector where their income is more reliable.

How can we have reliable long-term care for our disadvantaged in the community when often support work provided is casual work only; and therefore we lose well qualified support workers who choose job/economic security offered that comes with permanent hours.

Look after the **unpaid** carers. Do a profile on **unpaid** carers. How many die prematurely? How many die not long after the person they’re caring for, passes away?

How many smoke; drink; take drugs; are overweight; etc. Gym fees could be reimbursed to encourage healthy lifestyle (why not, when smokers : who aren’t necessarily carers; get their quit smoking programmes subsidised and drug addicts receive free methadone programmes; and alcoholics receive treatment as well as participation in AA groups?).

Unpaid carers should be treated: NOT IN CRISIS MODE; but in PREVENTATIVE ways; e.g. regular *massage;*physiotherapy treatments (often carers have back issues because of the nature of the work: this goes far beyond looking after the person who is physically disabled; but includes dealing with people who have oppositional behaviours; and for their own safety; often need to be physically ‘reined in’; or whose condition is such that the only way they can focus and learn is by encouragement and facilitation by another person. (Carers of people with physical disabilities often would need psychiatric assistance as well because it usually back-breaking work and the person with the disability can be very demanding). (My husband and I try to be responsible, and despite maintaining a mortgage; on one income and raising three kids; we pay private health insurance. Yet, despite this; a (thrice yearly) massage costs me $40 (i.e. $60 for the service; and $20 reimbursement from our private health insurance. This is approximately the same for any physiotherapy services either my husband and I require. How can this be, consider the demanding role of both of us as ‘parents/carers’?

Subsidised accommodation available for decent respite breaks (The Commonwealth Carer’s offers breaks but only when the carer has got to ‘crisis’ point: there’s that word again!)

Second dot point: ‘manages the costs of long-term care’: is it true that aids such as communication devices for the non verbal; wheelchairs; and other devices to assimilate people into an ‘inclusive’ welcoming, society, are free in NSW?

The ‘paid care’ industry needs to be seen as a VALID career option; and not something to do to earn some cash to supplement their own pensions; which has been the bulk of our experience with wonderful carers.
If the ‘caring industry’ was elevated to career status and included in high school employment expos; etc. it might open people’s minds to a career they hadn’t otherwise considered.

Point 3: guarantee that the disadvantaged won’t be worse off under the insurance scheme??

Point 5: accommodation: it’s everyone’s dream to live in ATTRACTIVE accommodation; and a decent neighbourhood. Can this be guaranteed.

‘aids and appliances’: I know of a woman here in Qld who had to pay $**7,000 for her own wheelchair**. Her income is the Disability Support Pension.

How dare people in receipt of such a miniscule payment have to pay for items when their disability is not through any fault of their own; yet the Govt. can afford to house refugees in 4 star motel accommodation?

Our son has autism and is non verbal: ; and if we were to purchase a communication device we’d be looking around the $5,000 mark!!!!! For a device that he could throw over a fence and wreck. I was told, not sure how true, that such aids (chairs; communication devices; etc) are free in NSW.

“accommodation; aids and appliances” etc. but no mention of the word “**therapies**”. We’ve spent a lot of money over the past 14 years with speech therapists; etc., and don’t get too much back from our private health insurance. Unfortunately the recently introduced, rebated costs for people with autism was introduced too late for our family as our son is too old (17??) to qualify.

Point 7: I would like to see this include encouragement and assistance to establish low cost private enterprises.

“education, training and employment” are included; but will either of these three include people who need 1:1 support; e.g. my son has autism; and intellectual impairment; and there’s very little he can do without support; however, he has proven that great things are possible with support.

In other words; will there for example, be education, training and employment programmes of various degrees (modifications) to make sure that the person with an intellectual disability or severe multiple disabilities is not ignored.

Regarding education: does this refer to:

Inclusive education;

And will it be

from pre-school to high school completion (and uni if viable). If it does include mainstream education; then it won’t work if parents have an option* of mainstream or special education units; or dedicated special schools; because society places a lot of pressure on parents to complacently place their children who need extra attention in with a lot of other kids with varying challenges.

Also adults with challenges often tell of personal, unsuccessful stories of their so called “inclusive” (mainstream) education; in which they were usually ostracised; and worse still, ridiculed. However, if the school culture was revolutionised and ‘normal’ children used to mixing it up with the ‘special needs kids’ I’m sure the stories of exclusion within a mainstream would diminish.

However, IF inclusion is the **norm;** then surely negative, unhelpful attitudes by parents of the ‘normal’ kids would also diminish.

We ‘dabbled’ in the mainstream education when our son was only 7. All the Queensland Govt. could offer was 5 hours per week of the 1:1 support he required to at best; remain in the classroom.

(Other parents of students at the school who had mild learning disorders, were resentful of the hours that were directed to him!).

- Special Schools should be dismantled; (or the concept of….) and the talent of qualified teachers and therapists from within, should be utilised.

Like all careers; our personal experience with the teachers at our son's Special School; is that there are 'good and bad' amongst them; and before offering them automatic placement within a mainstream school; their individual records should be scrutinised to determine their real values about students with disabilities.

Page 4 of the Issues Paper.

2. "How Can You Contribute to this Inquiry"?
First Paragraph: another reason for the frustration; is the lack of long term commitment by the Govt. to an individual. For example, we don't receive any recurrent funding. Our son graduates from Special School at the end of 2011.

I have a no. of small enterprise ideas for him; however, because I have no idea as to whether he'll receive funding for the start up costs; and the ongoing 1:1 support that will be needed to help keep him engaged in the enterprise; I can't take my plans too far. This is very unsatisfactory.

The Queensland Govt. is spending LOTS of resources on INCLUSIVE workshops; yet most of these workshops seem to focus on 'whether Freddy gets linked up with a fishing club on the weekend'. Wouldn't it be great if "Freddy" had a Mon to Fri life just like the rest of us. Maybe a real job, that gives him a sense of purpose and nurtures his self esteem. (This of course, would not be in a sheltered workshop; if one is to try and follow the principles of 'inclusion' for their son/daughter).

The word inclusive cannot be used by State and/or Federal Government(s); when kids with disabilities are 'excluded' into Special schools and sheltered workshop environments.

Paragraph 2 of Point 2 raises the question of "how to build a good system". Let's reword that to 'how to build an **excellent** system'.

The current Medicare system has some excellent features; and its recently introduced online services are extremely convenient. Why couldn't the disability insurance scheme be included under their framework.

All registered providers; e.g. surgeons; pathologists; occ. therapists; speech therapists; and (registered) suppliers of medical supplies/equipments; communication devices; wheelchairs; etc. could directly bulk bill Medicare.

Page 5: The Key Questions:

. **who** should be the key focus…………those whose lack of physical; intellectual; communication puts them in a position of HAVING to have support(s) of varying kinds to help them live a life with dignity.

. **how** they may be practically/reliably identified: babies; and younger children: paediatricians; GPs; (some disabilities are apparent immediate at birth; some through blood tests; however, the onset of autism commonly doesn't occur until approx 3 years of age).

Special Education Units of Primary/Secondary Schools; dedicated special schools' input should be valid; also therapists' (physio; speechies; occ. therapists; etc.); should be qualified to make calls on certain conditions (that aren't identifiable clinically).

Other ways: physio; speechies; occ. therapists; etc; surgeons; specialists; etc for acquired disabilities.

Ways of Achieving Early Intervention: training workshops for professionals; incld. physio; speechies; occ. therapists; etc; surgeons; specialists;
Parents to be more knowledgeable of what 'constitutes a disability'

General Note re: "who should be the key focus:

Current disadvantaged citizens and NOT JUST future ones.

I imagine that a lot of the respondents to the Inquiry will be people with disabilities (not too many with intellectual disabilities unless a parent; carer; guardian takes the time as I have in this); so please let the small voice of the person with intellectual impairment and mental illness (they're usually too proud to come forward); be heard loud and clear.

(I feel that **if** the Insurance Scheme is to only recognise FUTURE people born with disabilities; and acquiring disabilities; this is a kick in the teeth to people like myself; who are helping the Commission.)

What about the rest of the 'disadvantaged' community: would this be a breach of Human Rights and Equal Opportunities? Are they expected to continue on in a 'crisis-driven' system; in which the person who writes the best application for funding 'wins'?????

General Comments re the Inquiry:

Regarding the prospect of a national disability insurance scheme; it seems preposterous that we should worry about how to 'sell' it to the taxpayer, after all, how many millions $ are currently being spent under the Medicare system to fund people who have diseases relating to smoking; alcohol abuse; obesity; diabetes; heart disease; etc.; and methadone programmes for drug abuse; medical cover for people who've endured injuries from accidents as a result of skylarking. No questions asked about these recipients of taxpayer revenue; then why should it be questionable to assist people; who through NO FAULT OF THEIR OWN, have a disability (disabilities); that puts them in a vulnerable position of requiring lots of support to have some sort of a lifestyle that in some small measures reflects the 'inclusiveness' that we brag about.

Under the current system of current and non recurrent programmes; and the criteria for obtaining support from respite agencies; long waits to see therapists; etc there is a **perception** that if someone is in a wheelchair; the cheque book is automatically opened; no questions asked; yet the family and the person with the intellectual disability fumble along; hoping to be noticed. I'm certain this perception is inaccurate; and merely just the response of frustrated people suffering long waiting lists for support of some kind.

Therefore it would be great if the system was totally transparent; and to reduce animosity in the community (which in each town is a rather small community and people 'notice'). People who have questions about payments should be able query same, anonymously). Same for those who genuinely believe someone maybe rorting the system. They should be able to enjoy anonymity and be encouraged to 'dob'. Better still, they should be able to 'dob' without giving their names. The fact that someone has taken the time and bothered to lodge the submission; should be adequate reason to investigate the 'claim'.

On the other side of the equation, professionals, therapist; supplier of medical aids; and equipments; who raise their fees significantly at the introduction of an insurance scheme; should be 'scrutinised'. Acceptance of their provider no. may need to be considered very carefully; and made publicly available to current and potential users of that particular professional; therapist; supplier of medical aids; and equipments; etc..

In reaching out to people affected by disability(ies); some may not be able to articulate too well what their vision for such an insurance scheme could be; given that to date, any funding to assist the vulnerable in our society is ad hoc; based on whose written applications (in Queensland anyway) read the best (make that 'worst'); therefore, these guys aren't accustomed to thinking; planning; long term, and they're usually embarrassed about having to explicitly reveal details of their lives during application processes, that usually they're just grateful for whatever they receive.

How is the Commission's work re: Scheme, advertised/promoted: I found out about this Scheme by accident from a parent support group (in Victoria) though I live in Queensland!

A friend of mine with complex, physical disabilities, didn't even know until last Thursday (8 July 2010,) when she received my email.

She is a very articulate woman and her life's experience needs to be heard.

She currently lives with her daughter; son in law; and their family; but before moving to Qld, she was placed in a nursing home in NSW. Friends knew of her unhappiness and lobbied to get her out. The point to this is that this is a lady who could offer so much to such an Inquiry; but didn't even know about it til last week.

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Like all schemes **there'll be rorters for sure**; and as with private insurance companies; the Govt could employ 'random' inspectors to investigate large claims. Serious fines should be applied or an arbitrary period of time in which the offender can't reapply.

People should be aware of the 'inspectors' and such signage at point of claims; can remind 'applicants' of random inspections and consequent penalties.

As I said above: those who genuinely believe someone maybe rorting the system should be able to enjoy anonymity and be encouraged to 'dob' OR more effectively, inform, anonymously.

The growth of the incidence is of autism phenomenal; yet there is:

1. No Autism Foundation to raise funds to assist those affected by it (as there is with the Cerebral Palsy Foundation; Asthma Foundation; Skin cancer foundation; etc..

2. nor a research body to investigate the causes of autism. Until the cause(s) is(are) determined, no cure can be found!

3. Autism is often not discovered until approx. 3 years of age, so a scheme would have to make sure that these 'guys' are NOT precluded; i.e. don't meet the 'born with a disability' category. They are born with it; but it's not apparently until 3 (in a majority of cases);

4. People with autism are often discriminated against in that a lot of respite agencies naively believe that it is a ‘temporary’ condition; this may be the case with Asperger’s (a mild form of autism); but our son’s autism is the very low functioning one.

Approximately 18 months ago; he had the diagnosis of ‘intellectual impairment’ added to his ‘autism’ label; and it was only because he had that label; that he is allowed to participate in a local agency’s vacation programmes. I was told that because autism is temporary (in their minds) he wouldn’t have qualified for their programmes; but for the ‘intellectual impairment’ tag the Education Department has ‘granted’ him.

I am extremely disappointed about the way this Public Inquiry has been advertised; and from now on; I will be writing to all States’ newspapers; advising people with disabilities and carers of same; that this Inquiry exists; and also of my disappointment of its ‘promotion’.

A disability insurance scheme will definitely be efficient and therefore economical. For example, the Government is not going to continually pay (reimburse) speech therapy; occupational therapy; applied behavioural therapies (EXTREMELY expensive) for people affected by autism; and on the other hand, not set up a research body, into the CAUSE of autism!!
(and, of course, autism is but one disability).