SUBMISSION RELATED TO A NEW DISABILITY CARE AND SUPPORT SCHEME. BY URSULA SMITH August 2010

Key Questions with corresponding suggestions for change/consideration:

1/WHO SHOULD BE THE KEY FOCUS OF THE NEW SCHEME AND HOW MAY THEY BE PRACTICALLY AND RELIABLY IDENTIFIED?

a)The Issues Paper states "...the (new disability care and support)scheme is not intended to provide services to all people with disability,many of whom may need no or few supports. Rather, the scheme is intended for those in significant need of support. These would be mainly drawn from those with severe and profound disability..The severity of people's disability varies significantly. At the more severe end of the spectrum people are classified be the ABS as having either:

*a profound core activity limitation,where as individual is unable to do, or always needs help with, a core activity task (core activity tasks are self-care, mobility and communication) or

*a severe core activity limitation, where an individual sometimes needs help with a core activity or task, and /or has difficulty understanding or being understood by family or friends and /or can communicate more easily using sign language or other non-spoken forms of communication... "a)p7

Based on these definitions even people diagnosed as having "high functioning" autism or aspergers syndrome (often defined as mild) would by ABS definitions have severe core activity limitations by way of expressive/receptive communication deficits and therefore need to be included in the new disability care and support scheme. Higher functioning autistic persons with associated communication core limitations particularly need a new disability care and support scheme to adequately fund live assistance by way of integration aids in classrooms.

This would enable adherence to the priniciples set out in the United Nations convention on the Rights of Persons with Disabilities which states:

Article 24:"... 2b)Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

c)Reasonable accommodation of the individual's requirements is provided;

d)Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

e)Effective individualised support measures are provided in environments that maximise academic and social development, consistent with the goad of full inclusion..."b)p17

People with moderate and severe autism would fall under the profound core activity limitation category .

In determining through data the numbers of people with the greatest need of support there are several current problems to overcome:

a**)CSTDA statistics** are currently no worthwhile use in relation to disability and unmet need for policy-makers Australia-wide and in certain States and Territories due to the poor data collect methods and inertia on the part of many service providers. The "Findings Report on Respite Provision for People with Disability in Southen Metropolitan Region"(Melbourne)June 2009 states:"..Current and Future Demand for Specialist Disability Services (AIHW: June 2007) indicated the level of not stated/not reported for data across States. Victoria had a rate of 33.6% not stated/not reported for data on disability types, compared with 5.9% for NSW, 2.6% for QLD, 9.0% for WA, 5.2 % SA...NT 25.5%, ACT 50.9%. Nearly all categories of information except for age had similar or higher levels of non-reporting..."c)p8

This system needs to be overhauled in some states to be an effective data-gathering tool but limitations are that this data collection does not capture some unmet need as people on waiting lists up to three years are not deemed service recipients and therefore not incorporated in data collection.

b)**HACC data** does not capture unmet need as many people find the regulations of respite provision so restrictive/allocation of respite hours insufficient and/or costly that although carers care for a family member with profound or severe core limitations this form of respite provision is avoided in favour or flexible and free Commonwealth Respite Centre respite provision.

Also***, HACC files on individual community care recipients*** contain detailed information on the type and core limitation severity of the residents with a disability, plus the family care needs. Currently this extremely useful data is kept filed away with no analysis done of disability subsets and needs. Therefore policy making is hindered at Local government level by the non-use of this data*. This data is the most detailed data available for policy makers but it is unused/wasted.This data could be extremely useful for Commonwealth Policy makers in the new disability care and support scheme*. It is far more detailed than ABS or CSTDA data.

c)**A data base** which may be an effective tool for policy makers is a National Disability Register for specific disability types.
Currently there is no *National Autism Register* and based on the current data extrapolated from the CSTDA Intellectual Disability, ABI, Neurological and Physical Disability rates have remained quite constant over the years but Autism rates have risen dramatically. This follows the trend that 30 years ago Autism rates were 1:10000, currently rates in Australia are 1:90.

This rate keeps rising and due to the severe or profound core limitations of individuals by way of communication and self help these individuals are impacting respite services, education,health,legal and welfare systems,supported accommodation.Exacurbated by challenging behaviours such as absconding (running away from everyone/everywhere), pattern of injury to self/property/others.

d)The Issues Paper page 8 states:"...The **main source of disability** for those needing constant or regular support are physical conditions, mental illness, congenital abnormalities and intellectual disability..."(a)

The disabilities are categorised by the Disability Investment Group 2009 as:

*Congenital Abnormalities and Intellectual Disability,

*Nervous System Disorders

*Injury

*Mental Health

*Sensory

*Other Physical conditions lasting more than 6 months

Question is: Where does autism fit in to any of those categories? If a child with Autistic Spectrum Disorder appeared by all accounts "neurotypical" until diagnosis often made around the age of 2 years..is autism considered congenital??

I believe that due to the very high rates of Autism diagnosis of 1:90 children in Australia that the above information quoted by the DIG2009 is incorrect as Autism does not really fit into any category. Policy-makers need to factor these very high Autism rates into the new disability care and support scheme.

e)For intraregional and interregional equity to occur in service provision there needs to be *analysis of existing services* to determine the proportion of services which cater for "mild" disability, and those catering for people who have:

* challenging behaviours such as absconding;(4 absconding autistic children have died in Melbourne since Dec 2007. This equates to 1 death every eight months.(1train runover Strathmore,2drowned Yarra River,1 car runover Kyeton)
*injury to self/others/property;
*those requiring 1:1 feeding assistance such as dysphasia;
*those requiring 1:1 toileting assistance. Also an analysis of availability of accessible toileting facilities which impact accessibility to services/facilities.

THE KINDS OF SERVICES WHICH PARTICULARLY NEED TO BE INCREASED OR CREATED:

In regard to people/carers most in need of additional support and help:

In the respite/education/accommodation service industries there is a subset of people and their carers who are *excluded from services* which impacts the carers and families of those individuals.

These people as part of their neurological disorder have any of the following characteristics:

Absconding, pattern of injury to self,others or property I will refer to as *"untouchables".*

Due to Occupational, Safety and Health regulations these individuals are excluded from mainstream services as due to the low staff ratio (eg 1:15) these persons are considered an unacceptable risk to themselves and/or others.

The Commonwealth funds Inclusive Support Agencies such as Noah's Ark to provide an additional staff member in mainstream before/after school care and holiday programmes. This however does not cater for those in the above category as absconders and those who are injurious require 1:1carer support if the facility is insecure with external doors/fences/gates.

The Commonwealth Government does not have such a 1:1 carer support system in place in mainstream services so "*untouchables" are excluded.*

This new sort of 1:1 carer support system would enable adherence to principles in the United Nations Convention on the Rights of Persons with Disabilities which states:

Article 9:"..2State Parties shall take appropriate measures:

...e)To provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public...b)p9

Also, Absconders would be able to access *mainstream outside school hours programmes* if the Commonwealth required local governments to have one outside school hours facility based in a building such as a special school or adult day centre so that it was secure.

Accessible change facilities at the facility would enable people older than 3 to be toileted with dignity and therefore be able to access mainstream outside school care services.

These measures would take pressure off specialist services which are underresourced and the carers who cannot access outside school hours care in mainstream services or specialist services due to demand for services and places in programmes outstripping supply would *have more respite options.*

There are currently carers of students in most special developmental schools who do not have access to ANY before or after school care.

The Commonwealth funds mainstream outside school care but does not/will not currently provide this service for schools with high needs students. This is inequitable and limits the options of carers of school aged children to access fulltime employment if they so wish.
Carers of high needs students (albeit those frequently identified as most in need of respite) should not have to initiate and pull together funding from 3 levels of government as a funding model to create a before and after school care service for themselves. This occurred in the Melbourne suburban city of Casey.

Even this funding model has limitations because the Commonwealth source of funding was through the competitively-allocated funding "*Outside School Hours Care for Teenagers with Disability*". Teenagers in other regions do not have access to this funding as submissions are competitive therefore the system needs to change.

There is no Commonwealth funding "*Outside School Hours Care for Children with Disability*" . This is inequitable.

Solution*? Federal Government should "own" the issue and service provision of before and after school care and make the service provision inclusive and available for all students*

Waiting Lists for funding support packages and early invervention services need to decrease from wait lists up to three years as a priority.

For carers of “untouchables” mentioned above who are excluded from mainstream services and hardly receive any specialist respite provision due to lack of funding.. the *individual support packages* are the main life-line for families to gain respite. Long wait lists for funding packages push families caring for such persons to crisis point.Exacerbated by the delay in house modifications of doors,fences and windows to prevent the absconder escaping from the family home with possible tragic consequences.

KEY DESIGN ELEMENTS OF THE NEW SCHEME?

ASSESSMENT OF DISABILITY? Overseas models of assessments of disability such as in New Zealand are simplified and effective. GP refers child to Paediatrician for example who makes assessment of disability.

Cheaper method than Australian multi-disciplinary approach as same assessment tools used but by less Professionals. The system is of no cost (publically) to the individual or family either.

Benefits? Other professionals referred to such as Speech Pathologists when assessment needed to enable access to early intervention services. Free to Individual.

Paediatrician “owns” the child with disability and family care needs and also co-ordinates care through referrals to: respite/hearing/vision/speech/dental/psychologist/O.T./Social Worker etc and funding services.

Paediatric appointments are normally 6 monthly and carer has care needs discussed and dealt with by referral straight away.

In Australia a person with a disability and their family needs are not "owned" by any particular specialist so individuals/families can get lost in the system as it really does not feel "individualised".

Harder still for families with English as a second language.

CARER HEALTH ISSUES:

Factored into the new disability care and support scheme needs to be provision for the illhealth of the primary carer.

Carers undergoing cancer treatment are not usually given additional respite support from HACC services. Cancer treatments vary but the combination of surgery, radiotherapy and/or chemotherapy can take many months of strength from the carer's body to no lesser extent than an aged carer experiences (but is being acknowledged by Government and rightfully addressed).

A large amount of support by way of respite and home help is normally required by these carers so the family unit can function as smoothly as possible in such times. Challenging behaviours and lifting/running after persons they care for are too much of a strain on carers in those times and require urgent and significant infusion of support workers in the home environment if requested. Provision needs to be made for these situations in the Disability Care and Support Scheme.

COMPREHENSIVE VERSUS NARROWER COVERAGE:

- The scheme should definitely apply to people with existing disabilities who are in need based on the definitions of profound and severe core limitations plus new cases of disability which fit into that category.
- People experiencing short-term disability (7-12 months) should be catered for by the revised Health system instead of the

disability care and support scheme because if ABS severe and profound core limitation criteria are adopted then temporary mobility or self-help core limitations should be catered for by Health care in home support services. These limitations often result from injuries and accidents.

SHOULD ELIGIBILITY TAKE ACCOUNT OF PEOPLE'S INCOME OR ASSETS?

No. Carers of family members with profound or severe core limitations are always financially disadvantaged in comparison to the general population as numerous studies have shown. The burden of care is financially/emotionally/socially and economically great and does not relent for the life of the person being cared for with the severe or profound core limitations or self-care,mobility or communication.

WHO MAKES DECISIONS?

a)With individualised funding packages if it was deemed that the recipient of funds was incapable of making well-based choices or there is conflict of interest between the choices of care recipient and carer the Government could take up the matter with Public Trustees for an independent Guardian and Power of Attorney (handling financial matters) to be appointed.

b)Individualised funding should include the capacity to save some of the annual payment for future purchases of services

c)How would individualised funding work in rural and remote areas where service availability is poorer?

Carers/individuals can use funding to pay for 1:1 care support worker who lives locally so person has “live” support to access the community and/or have assistance to live in their accommodation of choice.

NATURE OF SERVICES:

a)There should be scope for minimal cost co-payment for some services such as occurs at present with respite services. Currently the co-payments between $15-20 for a full day respite service is manageable. Co-payments should be capped with knowledge that families with a people who has profound or severe core limitations frequently attend specialist schools which lack outside school hours services(therefore income options are limited for families).

b)Challenges for delivering expanded services in remote and rural Australia are often overcome with proper cross-sectional community consultation moulding social policy decisions and consequent service systems.

c)How can services be co-ordinated, both between disability services and with services provided outside the system?

New Zealand system works well with paediatrian for children referring to services provided within and without their disability system.

The Australian Commonwealth Government needs to own" disability",create better data gathering systems, analyse gaps and delays in current service provision and correct ineffectual service systems.Paediatricians could be part of the streamlined service system as the lynchpin between care recipient/carer and new commonwealth-co-ordinated Government service system

HOW SHOULD PEOPLE'S NEEDS BE ASSESSED?

If Long term care needs are assessed against severe and core limitations then communication,selfcare and mobility core limitations aren't likely to vary much short or long term so why keep reassessing??Carer needs are more variable. Suggest a nationally consistent Supports Intensity Scale be devised with reference to core limitations suitable across all disabilities used by Paediatricians for children or disability-specific specialists for adults.

GOVERNANCE:

How do people know what services are available to them? Local-government produced brochures outlining disability services available locally,information fed to local government from Commonwealth.

References:

a)Issues Paper: Productivity Commission Australian Government 2010;

b)United Nations Convention on the Rights of Persons with Disabilities;

c)Tender No:T0802 Department of Human Services commissioned document prepared by Springboard Social Planning: “Findings Report on Respite Provision for People with Disability in Southern Metropolitan Region, June 2009