Personal response to the Issues paper: Disability Care & Support

My name is Valerie Johnstone and I presented at the Melbourne consultation and further met with Ms. Patricia Scott and Mr. Ralph Lattimore.

Background:

I am a social worker by profession and have worked primarily in health (rehab , aged care assessment). I have a significant vision impairment (optic atrophy) which is degenerative, hence some may say that I am a work in progress. Nonetheless, it is all to do with attitude and approach to living. I have two adult children, my daughter Fiona is 36 years and has Downs syndrome, my son is estranged from us with many "social" issues that challenges the notion that it is persons with disability that are the problem and constant worry/burden. I was widowed in 1990 hence had to make some courageous decisions re Fiona's future that facilitated independence and room to grow, that was sustainable i.e. well thought out plan, building an environment where she had control and took responsibility, and above all believing in her dignity and jois de vie.

When I spoke of us being an atypical family, the sub-text is that we had a vision and expectations for Fiona; disregarding poor "advice" , recognising that there was a window of opportunity and focussing on understanding **how** she learned and then set about the task of teaching, reinforcing being generally supportive of her getting on with the basic learnings of life . The examples that I used at the consultation was the ability to read, independent and confident travel (mobility), and fostering social exchange . It is over 13 years that Fiona has lived on her own – to give her security of affordability and tenure I purchased a unit that became available a few houses down from me . and she moved in with some hand me downs like many other young people, she pays rent (albeit far from a market rate, just enough for me to cover expenses of property ownership. The start was a modest one (being safe, personal care, basic meals, banking and bill paying, shopping) the aim was for it to be a positive experience and a foundation to build on her successes and that has certainly occurred; since receiving recurrent direct payments the guess work and ongoing concern of a primary carer has been removed. She has grown so much!

For me, it is about having a considered (evidenced) approach and a fundamental belief in the dignity of persons, citizenship and participation. Identifying issues early and making a decision will have many benefits over the years (early intervention),, long term benefit e.g. slow recovery for ABI . Enabling rather than gate keeping, what are the rewards, is it that inadvertently , dependence and/or deficits are being reinforced ?

My personal and professional experience, insights and can do approach got me a seat on the inaugural Disability Advisory Council of Victoria, which led to representation on other policy driven reference groups, one of these being Direct Payments (which I discussed in detail with Patricia and Ralph).More recently have been on the Disability Reference Group of Victorian Equal Opportunity & Human Rights Commission

I know many people with disability (pwd) in all sorts of life situations , service organisations and advocacy sector, all sorts of contexts which has contributed to the breadth of my observations and insights re the issues, concerns, scams and flaws. I know that Victoria has some runs on the board in striving for better outcomes nonetheless it is not easy and we have the evidence from many reports “Shut Out”, Senior Practitioner Report (Victoria) and many more, nonetheless I want to highlight some issues below, also propose some ideas for system change that will impact on the deliberations of the Commission in considering the various aspects of Disability Care & Support .

* Obviously with the CRPD and the National Disability Strategy many policies and programs will be scrutinised; asking the question of where are the rewards/incentives to maintain or change /transition behaviour that has mechanisms to track and slowly but surely change existing negative culture.

For example, in many situations, the pooling of the pwd’s pension with $10 pocket money. Co-dependency and sabotage of change opportunities is evident; the unfortunate situation is that as these primary carers age, their anxiety for future placement increases and for the pwd it is almost too late to learn/adapt to minimal/low care and the demand for higher care increases (often showing up on homelessness and/or “unmet” needs registers).

Likewise , the current emphasis of the respite program is not necessarily useful and conducive to positive relationships. Also, policies that enable young people being “placed” with organisations that attract government funds little recognition impact on individual (of grief, loss and connection to health and well being).

*** while there is a role for government to manage infrastructure issues and much work is underway in various areas; the lesson is universal design not only in buildings but in service delivery, hence participation for pwd and those with care responsibilities in education, employment, sport, arts, volunteerism. It is about being meaningfully occupied which has huge benefits as citizens and learning about healthy and respectful relationships.**

*** The case could also be made to the business sector that they are a legitimate stakeholder as pwd get on with living in the community and rather than being a hit and miss approach it could be a considered development of a point of difference (e.g. escorted travel options for older Australians, supported travel options for pwd) Smarter use of technology and thinking laterally re a business idea, for example twenty years ago the only option for older persons requiring a nutritious meal was Meals on Wheels, well now there are a range of competitive options Not about separate (too expensive) just incorporate with a few tweaks!.**

T The rationale and eligibility for the Aids & equipment program could be scrutinised and simplified guidelines to enable a range of pwd to access enabling equipment and/or modification of work/home space . . Not just wheelchairs also equipment for blind/vision impaired which is very expensive (DAISY from NILS is information provision but not necessarily portable / flexible and meet the needs of individuals.

> IDEA 1. Aids & Equipment Program
> 1. PWD request information brochure which describes eligibility, process, costs – State $, option to upgrade with own contribution. agent's responsibilities (warranties) & customer responsibilities (conditions of use, etc.) 2..Apply for equip/modification that states information about you & disability, why you need the x, how it would make a difference in short and long term 3.Quick turn around of assessment, successful applicants will receive a referral to x, a redeemable voucher, and/or cheque for set $. 4. Corroborate purchase and benefit of the equipment and forward to program administration. **Must break the nexus of the closed shop, duplication and unsustainable bureaucracy whose current aim is far from enabling , seems aim is to say "No!".**
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> **Similar to the role of broker when making decisions re health, or home insurance ; I do believe there is benefit in the development of the broker re the aids and equipment program — role would be to do the compare and contrast – including items available in non-disability shops — discussing warranties , limitations of certain options and benefits of others basics of fair trading etc. Currently, the various independent living centres or equipment showrooms only showcase the high-end/specialist items hence quite expensive; there are many generic items that pwd do not access the only reason being that they did not know the item was available , had not done the lateral thinking or worked out an everyday solution.**

***** There are many issues with current disability service delivery, hopefully the Quality of Care Framework will address some of the issues to do with disability specific services. We need standards that are evident in practice , including clarity on qualifications. Disability service organisations range from those that are government managed, funded , non-funded that provide a range of HACC type services attendant care and independent living/community support services. lack of clarity re Different funding sources and policies inevitably this leads to slippage and poor accountability. Having $ to purchase services is only one aspect of the equation – standards and mechanisms to address issues are critical . Also, the possibility and know-how to use as many generic services as possible or market place specialist service (such as Leisure Options, that we have used for Fiona's holidays) that are bound by professional and industry standards.

* Significant issues are consistency of service and consistency of resource allocation (size of packages) , there is poor data and a policy issue that does not have some clear frameworks and a bolt on model. A pwd culture that is set on as much as rather than needs that are quite specific. I know there is a piece of work being commissioned by DHS Victoria to look at resource allocation ; however, I

do believe that it is about using a worker time smartly acknowledging that resources ($, and worker hours) are finite. Simon Duffy from In Control was very clear about this as well.

> IDEA 2 Better Outcomes From Direct Payments
> In Victoria, there is an option for individuals on an Individual Support Package to receive funding as Direct Payments. Few categories of funded purchases, It is about becoming a savvy consumer and making "your" $ go further. For example, Fiona prefers to have **four** movie tickets which she uses over three months rather than **one** "specialist" 2 hrs. rec. activity that is not particularly fun, and reinforces segregation.
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> In Fiona's case I have a basic contract with a service provider that stipulates required hours and frequency , process to manage changes, tasks required and importantly preference of worker (gender, age, attributes) The account is paid monthly (fortnightly invoices)e , whatever the rationale by organisation the hourly rate is $29.47 , significantly less than DHS unit cost per hour. This works well and defines responsibilities
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> A new system could develop to have an acquittal/reconciliation akin to a tax return; for individuals with large budgets a quarterly system e.g. business activity statement, Definitely about simpler, transparent, and accountable The brokerage model used by CACP and Linkages could be an option for those who require and could benefit from using a broker. Also need to think of mechanism of refunding unspent funds.
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> N.B. In Fiona's plan the direct support budget is 7 hrs p.w., however she mostly uses 2 ½ hrs. p.w. (each week, it is the budget, planner, and small/easy cooking +one week it is big shopping (fruit & veg, supermarket groceries) and the other it is big cooking (meal that is divided into four serves). Of course there is flexibility, when jobs get done in good time Fiona loves going over the T.V. week, playing a board game, etc. With the Community Participation $ there are 3 strategies, 1. **learning** two sessions a week at Sandybeach Centre and Council of Adult Education doing a supported Certificate in General Education, 2 days a week . 2. recreation , Hoyts movie tickets, local theatre group (5 plays per yr) some activities with Club 21 run by Down Syndrome Victoria for young adults; 3. **time out** $1000 towards a supported holiday.

- There are many community organisations that call themselves and are funded as "disability advocacy organisations", however, the criticism is "whose voice?" Many do not have a membership fee and little or no mechanism to canvass issues and to prioritise. Lack of accountability to membership and to funders alike. More troubling is the nurturing of anxiety/fear rather than a constructive approach (this was even demonstrated, in my opinion, at the consultation in Melbourne).

Currently there is a review Draft National Disability Advocacy Framework, out for comment, of course quite some navel gazing as the organisations resist change and their future role . In Victoria there is a Disability Advocacy Resource Unit (DARU) and Self Advocacy Resource Unit (SARU) that is trying to address some of these concerns with code of conduct etc.

Mr. Bill Shorten makes the point that there is disunity in the disability sector and community – duh! Excuse me sir, that is just a product of the funding models whether it is a service provider or advocacy (e,g, blind, deaf, paraquad) ; sadly , some advocacy organisations had in the past tried to play the politics of envy game, I do believe that this has been debunked with the good work done by Australian Federation of Disability Organisations (AFDO).

*** State governments have a specific role; structures that have the capacity to address systemic issues must have better outcomes for the community which includes pwd and/or families. State and local government are critical to building /nurturing informal networks**

Community Health Services that can be improved have long term benefits; both LGA's and CHS deliver HACC and other services. From my work in Health (especially Primary Care Partnerships (PCP) it is evident that many councils have many facilities that have been built with C'lth and State monies for little community dividend i.e. rooms used on a venue for hire basis model rather than other councils that by using a community development model run a range of activities that are of interest and overall benefit to community health recognising the link between social determinants and burden of disease, and that such a focus had benefits for all of the community .

* Fundamental recognition that pwd have a right to timely and appropriate health care, housing, education and employment. Access to each of these have huge benefits. Health is something that I know about in it's knitty, gritty and have some examples below for consideration. I have called this intentional as it certainly could be developed as a suite of "scripts" for G.P.'s and/or health professionals.

IDEA 3. Intentional Health Promotion

I know there is a lot of work being done in Health Reform, I am very involved at various levels in Victoria, however in relation to Disability Care & Support I would suggest that simple things can be done that would make a big difference for individual, also, short and long term Health budget. Here

Here are some specifics G.P's need to have a pro-active rather than reactive approach when managing issues for pwd; that utilises a range of Community Care services or other low cost /bulk billed

services. The development of business case to develop suite of para health professionals to address the issues of demand, benefits of prevention, and workforce issues.

Podiatry: Pwd with sensory and cognitive disabilities are on their feet a lot and not the most able to manage their feet health . Likewise pwd in w'chairs can not rely on non professional to be aware of risks in cutting toenails etc. . My daughter Fiona has a three monthly appointment that costs $10 but which gives us peace of mind, she receives good information and care in managing her feet.

Physiotherapy: There is much evidence about Falls Prevention . once again G.P.'s could be targeting this aspect in management plans for pwd, sooner rather than later. Many friends of mine in chairs emphasise the importance of maintaining ability to do their own transfers independently for as long as possible , surely this has to be encouraged along with general information of nutrition and managing a sedentary life, Baker IDI modified physical activity program for those with a predominantly sedentary lifestyle needs to be available more generally. . The other less spoken of issue is importance of reducing incidence of incontinence, learning some basic pelvic floor exercises has many health benefits.; besides staving off earlier entry into high care.

Occupational Therapists: Annual reviews (done when new plan is developed) could include a visit/information , etc. re new ways of doing stuff whether it is simple ideas of new technology. This is also very beneficial for many with medical conditions who would certainly benefit from learning about simpler ways to manage their episodic and often degenerative medical conditions .

Oral Health: I have known of some shocking examples of poor oral health – the consequences are disastrous, yet, establishing simple processes of information, dental nurse role enhanced, and annual check ups would be beneficial to all concerned.

* **Many community organisations have DGR status and are beneficiaries of philanthropic grants and community donations, lack of scrutiny and an informed view as to the impact of practices of funded projects e.g. negative images/stereotypes. For example, Vision Australia (and others) recruit volunteers not to support their clients (many older Australians with macular degeneration and other vision loss) but to reduce their paid workforce while reducing the nature and scope of services e.g. no home/in situ assessments. Once again bare minimum provided as a funded organisation, minimal responsibility for long term consequences for client and community**

- **Clear policy that engages all stakeholders – individuals, families, community and State. Government leadership in using the Convention on the Rights of the Child to support kindergartens, schools, to manage the occasional ugliness and stigma that may occur in playgrounds etc There are some great initiatives e.g. Best Start , Hubs for children's services; however I do believe that the community conversation has to be had, so as to address scuttlebutt.**

  Development of clear understanding of roles and responsibilities to young and adolescent children so as to create a culture of participation . As an incentive to plan families should be cognisant of Special Disability Trusts and/or like vehicles so as to ensure that a legally deemed dependent child is provided for adequately when estate planning as assets allow. Recommendations by the Senate Review could be considered and State governments could remove land tax for this property and the stamp duty to transfer into Trust, given that no $ changes hands, and have it paid on the sale of the property.

prevalence and incidence

I would support the key principles and objectives in the issues paper, with a couple of mentions 1. the Deaf/Blind are a group of people that have very special needs that are not being addressed adequately; not only about communication also, many other activities of daily living.

2. many medical conditions that are disabling are managed relatively well for many years, however, many issues are exacerbated as they are degenerative (like myself) and as person ages hence timely and targeted support is required, if this is to be absorbed into the Community Aged Care Package (CACP)it could well be of benefit to identify these groups with long standing impairments so as to create a different category or prioritise. The aim should be to reduce the incidence of institutional care –with a real possibility to continue living in the community.

Rationales and objectives for a long term care and support scheme

A long term care and support scheme is not just about funding – as some would have it – it is about system change; public monies need to be accounted for and thus far block funding has not delivered and is not sustainable. It is about raising expectations — of all stakeholders so that they have a vision and can plan. It is also about shared responsibility; individuals that, and are encouraged to, step up to the plate, families that understand their role as parents, siblings, other in the life of a child, teenager, or adult.

State and C'lth funded policies and programs that are determined to effect change by understanding and implementing the CRPD, National Disability Strategy, National Arts and Disability Strategy and so on. As Mr. Bill Shorten insists there is an economic, local government and Education, Transport, Employment, health services that have responsibilities for communities and implementing policies and programs that are funded to effect change.

The business sector that gets engaged and consider that pwd still need and want to engage in the communities that they live in.

In essence it is an ecological approach, not just a nice diagram but real work by all.

Design elements:

There are models that work well and can be considered, such as TAC Victoria. Also models such as In Control and the Community Hub model in Canada.

The scheme as such should be simple to use and transparent . It should be fair and have options for persons to contribute. Incentives for studying /employment albeit part-time if need be. As mentioned above incentives for families to play a role.

of have made many comments in relation to policy , obviously these are decisions for recommendations that will impact on design. .

Eligibility:

Please note that current eligibility for many services that pwd require is pension or health care card, by default this is a disincentive to persevere or seek employment ; there needs to be some recognition that for many the income earned is low (only work for limited hours p.w.) For too long a DSP has been associated with "unable to do" rather than a recognition that they can do differently and the requirement for health services, aids and equipment , and other support services.

Eligibility criterion needs to be clear given that there is such a difference in individual experience ; not just impairment, also functionality and where it happens (environment) . Possibly consider a tiered approach , or different categories;

1. those with severe/profound disability that need long term care and support. HACC and intentional G.P. services, set aids & equipment budget.

2. those with sensory , moderate physical disabilities (congenital or acquired) that could enhance independence and quality of life with access to HACC, intentional G.P. services, targeted budget for aids/equipment .

3. those with medical conditions that can be disabling, episodic by nature , often degenerative, and can benefit from access to HACC , intentional G.P. scripts and a small budget/ voucher to purchase some item that would enhance quality of life.

Re means testing, I do believe that it could be non means tested so as to be an incentive to be involved with employment etc. . Even children's care should be provided so as to keep the workings of the family ticking over.

Nature of services:

In 2010, services for pwd is about attendant care for those with a physical disability and independent living support for those with a cognitive disability; I do believe that the nature of services will evolve. There needs to be a mechanism as to sharing of such information.

Decision Making:
Please refer to comments on governance

How much? Entitlement:
Once again many models of assessment can be analysed.

Financing options:

I would support the proposed Disability Insurance model for the funding of an individuals disability support and care.

. At the Melbourne consultation Ms. Raelene West spoke passionately against the "no fault" principle. Maybe, it is about conveying clear messages — yes, we want to short circuit the legal merry go round of obtaining compensation, however the issue of liability and victim retribution could be addressed by an amount being paid to the insurance scheme. Similarities with Family Law Act that is "no fault", nonetheless mechanisms for property settlement , child support, etc.

Special Disability Trusts needs some more work; for a start surely the key criterion should be that the pwd is able to live independently with support; no point in just having a house and then demanding round the clock care and/or establishing an institution by default. State can certainly acknowledge their role in enabling . However families need options to make it possible. Also, the management of these Trusts families need far more information that includes advantages and disadvantages. I consider Special Disability Trusts as a vehicle for families to plan and provide for a child with a disability in the future, mostly a roof over their heads and monies to ensure that associated costs of property are available to administrators.

Workforce Issues:

There are major issues, poor standards , driving <u>down</u> quality — in short the service providers have funders over a barrel! My concern is that the ageing of the population – including all those ageing primary carers — will inevitably create more demand for services especially when pwd have not developed independent living skills .I do believe that it is not just about managing demand but managing the quality and ultimate safety and well being of service users. I have given this a lot of thought; here is a summary of my ideas:

- **use as many aids to assist in being as independent as possible.**
- **Clearing house (staffed) of basic and/or innovative ideas (including smart technology) to give person more control and buy in .**
- **Discouraging the casualisation of workforce, price must drive higher percentage of part-time/full time workers , retention and training .**
- **Identifying , quite precisely tasks required for a shift, , and hence what you pay for – the variation and flexibility comes in the when , where, what order of priority, etc – by doing this it can be worked out if there are other options e.g. using a laundry service.**
- **Using as many generic services far as possible ,**
- **Explore the notion of shared kitchens to do some meals similar notion to community kitchen but on a smaller and informal scale (shared worker) , shared meal and some meals to store for the week.**
- **Parity with workers across sector (aged, early intervention, pwd).**

Governance and Infrastructure:

This is paramount . Based on the evidence and all of my earlier comments in this submission pwd cannot be done over yet another time!

At the individual level the person must be expected/encouraged to make responsible decisions as to how support $ is used. Likewise, the responsibility of nominated person to enable understanding and act in best interests of individual.

I am sure that the Commissioners have plenty of information on hand to ensure that the many issues of governance are addressed at the different levels; pwd need to know that there are clear lines of accountability, clarity of policy and programs that benefit their quality of life.

Costs, Risks, & Benefits:

Mr. Bill Shorten is emphatic when he makes the point that there are economic social, and civil benefit in re-thinking the approach taken thus far to disability. Some years ago I made a similar point, to DHS Disability Services, with the comparison that it cost the State $260,000 per annum (at that time) to keep a person with an intellectual disability in a CRU (the person had no autonomy, little confidence and self esteem, and very little skill development) , in Fiona’s case the State individual package received is currently just over $14,000 per year yet expenditures had never exceeded $10,000 per annum and for that Fiona lives with a high degree of independence, had a sense of autonomy, control, and many opportunities for growing in skill development and growing of confidence .

I do not understand why “collectives” have not tried negotiating a wholesale price (i.e. if x hrs used over given period). Likewise, lateral ideas like Support Bank or a service that only does personal care between 6 – 8:30 a.m. , similar model that is used with office cleaning that only occurs within set hours.

Surely, the various Justice Departments with are responsibility for the Fair Trading Act , need to come on board and develop strategies that address issues experienced by pwd whether it is equipment or poor service delivery.

Concluding comments:

I have tried to be as forthright and thorough as possible in this submission, as I do believe that I owe it to many pwd who yearn for improvement in their lives.

As a modern and democratic society we need to take stock and amend those systems that serve no purpose in enhancing the lives of vulnerable people.

Finally, I thank the Commissioners for all their work and commitment in this huge and daunting endeavour.