disAbility connections
(victoria)

81 Cowper st
Footscray 3011
Ph: 9687 7066
Fax: 9687 5621
Email: Helen.dcv@annecto.org.au

I write on behalf of the members of disAbility connections (Victoria), formerly known as the Western Region Disability Network. DCV is a network of individuals with a disability, their carers/families and those who support them including professional staff, other networks and support groups. DCV membership is open to all disabilities and all ages. We focus on the Western and Northern suburbs of Metropolitan Melbourne. DCV (WRDN) was established in 1993 and has a membership of just under 1000, with approximately 65%identifying as a person with a disability or a carer/family member.

DCV would like to commend the concept of a National Disability Insurance Scheme as the only way to ensure that the human rights of every individual with a disability (and therefore those who support them) are met. The current system is in a crisis and therefore many people with a disability find themselves in a crisis too. There are insufficient resources to meet need administered by a bureaucratic, complicated and inequitable system. We respectfully implore the Productivity Commission and the Governments that are going to consider and implement the recommendations as a matter of urgency.

As I answer the questions that the Productivity Commission has specifically asked I will put forward some examples from the membership about the impact that the current system is having on their everyday lives. This is not so much to highlight individual issues but to illustrate our points.

Who should be eligible?

DCV members considered this question most carefully and came to the conclusion that everyone who identifies as being a person with a disability and/or the carer of a person with a disability should be eligible for support. The reasons we came to this conclusion are twofold.

- Social justice- if you believe you have a disability and that you would benefit from support then you probably do, and therefore you should be able to access the support you identify whatever it is. In our experience (and most members of the DCV have been living with disability as an individual, carer or paid worker for many years) people tend to underestimate their needs rather than over estimate; people do not choose to be labelled as having a disability unless they are forced to do so in order to access the assistance they need.
- Financial – the more time and effort you put into trying to determine who is or isn’t eligible the more money you need to spend on the infrastructure to enable these decisions to be made. Would it not, we thought, be better to redirect that money from maintaining an expensive bureaucracy (which is what we’ve currently got) to spending that money on

supporting people? It probably wouldn't cost more; in fact we thought it could cost less because the bureaucracy is very, very expensive. So are appeal processes and the paperwork, time and energy it takes for everyone to fill in forms, check and process forms and more forms.

We would like to give a couple of examples here:

- Someone had a very ill child and needed a support package. All the paperwork was completed as a matter of urgency and off it went to the Department of Human Services. Five, yes five, months later the parents started jumping up and down - desperate now – where was the support? It had been through 5 layers of the bureaucracy – each looking it over, agreeing it was reasonable in the circumstances, rubber stamping it and moving it upwards. The trouble was that it still wasn't there yet. Why we ask did it need so many ticks before it could be processed? Why was it so complicated? Why did it take so long? Why was it only approved finally after threats to go to the media and how did all these people think the family was managing while they fluffed and discussed and it sat in "in-trays"? The whole process must have cost a fortune but it achieved nothing tangible or positive.
- One of the DCV Committee of Management has a self managed package of care for both his elderly mother and his daughter with a disability. It took him years to get the various departments to agree that he could in fact be trusted to manage these funds properly. What he discovered was that 12-15 hours of direct care expanded to 35 hours of care when he removed all the "middle-men" and managed the money directly.

DCV members clearly stated that this should be a fault-free system. The current practice of treating people differently because of the way they acquired their disability is not only unfair it's downright undemocratic! People do not choose to be born with a disability anymore than they wish to get MS (Multiple Sclerosis) or any other neurological condition. Just like they don't choose to have a road trauma or a workplace accident. In fact sometimes work or vehicle injuries are self induced but I don't know of any unborn baby that gives itself an intellectual or physical disability. We compared 2 of our members:

> Person 1 acquired her disability through a car accident. Through the TAC she has received house modifications, aides and equipment including a motorised scooter, free medical services with therapists and case management support. Person 2 in comparison acquired MS. Had to buy a new house so he could get physical access, bought his own wheelchair (finding out 5 years later he might have been eligible for a subsidy), no therapists, no case manager, no pension and no support. Both need assistance and in fact person B's physical disabilities are more severe than A's

DCV would like to propose that only a few people with a disability should have to meet eligibility requirements. These would be people who have a disability that may not be life-long (although quite debilitating at the time) e.g. bad backs. While we would like to see the focus on people with higher support needs we recognise that an impairment becomes a disability if the person cannot access the support they need. Support in this context may not be direct care but access to things like hearing aids, wheelchairs, and house or vehicle modifications. These may only be once off but if you cannot afford them your life becomes very difficult. An example:

> "My husband is deaf-well almost totally deaf but he can hear with hearing-aides. But they're so expensive. Even a cheap one is $2500 and he needs two. I didn't realise what a disability we both have until he lost one. He couldn't hear and I had to yell and listen to the TV at about 4 times the level that was comfortable for me. To make things

> worse he couldn't hear anyone else either – making it dangerous for him to drive, to work or just to cross the road".

We would like autism to be considered as a disability. At the moment you only qualify for disability supports if the autism is combined with an intellectual disability or another impairment. Autism itself comes under Mental Health. But people with autism have a really disability in that while they may have average (often above average) intelligence they find it difficult to interact with the outside world. The "mad professor" comes to mind – brilliant but rude and antisocial, can't make a sandwich or tie his shoelaces. The impact this has from childhood onwards is catastrophic.

<u>Who has the power?</u>

If the scheme is an opt-in, easy to access scheme that doesn't make you jump through hoops to get your needs met then that automatically puts the power firmly in the hands of the individual with a disability (or for those with higher support needs in the hands of the carers/family).

If the scheme supports people identifying their own needs then they are the ones who direct their entitlements and that gives them the power.

As stated above our experience would be that, if anything, people ask for less rather than more. People are not 'silly' – they know that even with a tax payer funded scheme there isn't going to be a bottom-less pit of money. People don't want to be beholden – they want to be assisted so they can be as independent and "normal" (how we all hate that word) as the rest of society. The social welfare system already has strong powers to deal with people who rort the system – we don't believe there are many who would do this on purpose but we endorse strong measures against those that might because it's our money (we are tax payers too – support us and more will also be paying the tax)

There is a lot of debate going on at the moment about the shift away from traditional service delivery and the ways that organisations are funded to provide disability supports. There's a lot of debate about the positive and negative outcomes of a user-managed system of funding. There are many members of DCV who would like to have the opportunity to self manage (or be actively engaged in managing) their package of support – the issue is they have to "be approved" to do so and what was funded on a group basis has insufficient money for a more individualised service. This is proving a challenge for individuals, families and service providers combined.

DCV would like to respectfully ask the Commission to give extra weight to the views of individuals, carers and professional staff. We say this in the nicest and gentlest way possible, remembering that some of our members work for or are organisational members of our network. We have the greatest respect for the people who work in the organisations (government, disability specific as well as generic) who do their best every single day to support us. We have never met a person working in this field who does not demonstrate a passion for disability issues. But sadly the reality is that there is a conflict of interest here. Organisations have a vested interest in retaining some of the power because they are at all kinds of risk if the power is transferred totally out of their control. They have a need to retain some degree of the status quo e.g. if we remove the need for bureaucracy what happens to all those unneeded, well-paid public servants?

<u>How should the amount of financial support and service entitlements be decided (and by whom)</u>

As stated above we firmly believe that people should get the <u>all</u> the supports and <u>adequate levels</u> of support that they self-identify as needing.

While we agree that someone needs to authorise this we do not believe you need several layers of bureaucracy (as in our example above). Maybe, we thought, one person to work with the person to put together a plan or proposal and then one more to authorise. What may be needed are some "specialists" who assist with costing what people say they need e.g. Mrs Smith identifies a need for a new wheelchair for her son and an accessible bathroom once he has one. So obviously someone to assess his needs (maybe he doesn't need a wheelchair but other options that Mrs Smith is unaware of), measure and fit a wheelchair to the person and ensure it "fits" the home environment but then maybe a specialist designer for the renovations.

The amount of money could be capped according to the assessed level of need (e.g. an assessment at critical points of time such as on-set, early intervention, entry to school, movement to high school, end of school/adulthood, leaving home, etc) but as we stated above we believe the vast majority of people will only ask for what they possibly can't manage without rather than exaggerating their needs.
As we will discuss under funding this whole process can be streamlined and made easier by just a few adjustments.

Two points we would like to emphasise:

- Very rarely does disability "go away"- there may be some gaining of skills and independence (especially if the required supports are provided at the appropriate times), though more often especially with physical, neurological and sensory disabilities the condition may in fact worsen so
- There is no need for people to be continually assessed, re-assessed and then double checked on. This is a waste of resources (including the poor GP's who get to fill in the forms) and peoples time and energy. Instead we suggest that expanding the proposed electronic medical records system or linking it in some way would mean that people do not need to consistently retell the most basic of information. Saved money can be directed into service provision

What services are needed and how should they be delivered?

People with a disability are all individuals and therefore what they need will be tailored to each person but in general the membership says that what we need are:

- Assessment at on-set (whether this be birth, realisation "my child's not meeting milestones!", trauma, illness etc) – so we need more people trained to undertake things like autism assessments, etc
- Counselling services – facing "disability" and all that implies is terrible, people need to be assisted to understand this and what they will be facing.

  > "I worked with a lady in her 80's who told me that I had, for the first time, given her permission to grieve for the child she had expected and the life she had dreamed of. Not that she didn't love her 60 year old son but where were her grandchildren, her independence and her life".

- Early intervention services (because its universally acknowledged that early intervention pays long term dividends in terms of both quality of life but also a marked reduction in reliance on supports across the lifespan)
- School support services- properly trained Intervention aides, training for teachers about how to teach and integrate children with a disability

- Employment support and schemes to ensure that there are real jobs for people with all kinds of disabilities and all levels of ability.

> "Some of my job seekers are highly qualified, but they are on the training treadmill. How many courses or degrees can you expect a person to do before they realise that people take one look at them in their wheelchair and think it's all too difficult? And you know who are the most difficult employers to crack – yes! Government departments"

- Respite services including facility based (to support people with higher support needs or where the carer needs a longer break)

> "We need facility based respite because ... can't go on camps or outings. She has medical conditions and can be very difficult. We don't get enough respite because DHS keeps closing the respite houses, and when we do get a booking you can't rely on it. Often we've been asked to cancel our booking because the bed is needed for someone who is living in the respite house – sometimes 3 people out of the 6 beds"
>
> "Our community helped us open an accessible respite house. We have community support, volunteers etc. DHS will send people to us for respite but refuse to give us any money towards funding it. Why? There's no other service in our area – one of the growth areas of Melbourne"

- Community based respite support including recreation, camps, groups, discos and in-home support , with our choice of provider – including the right to find our own carer (that anyone else would call a babysitter) and pay them from funding
- "I would like to use my Council carer as my in-home carer but I can't because the Council charges more than DHS will pay. This means rather than using someone I have confidence in and who knows our family we have strangers who know nothing –and we spend half our respite time explaining what they need to know."
- DCV membership recognises that they are many, many people with a disability who can access main stream services but there are many that cannot. Individuals, families and service providers need to work together to ensure there are a range of services that people can choose between. And that those services are viable, staff are properly reimbursed and trained and people are fully supported. No-one wins if all the service providers shut up shop and go home.
- "There is such a push to community based but really there's a big difference between being physically in the community and an accepted participant in the life of the community"
- Assistance to get and maintain an independent life in adulthood. This means the ability to leave home if this is appropriate and what you want to do. This means accessible housing, public transport, accessible (both physical and attitudinal) community activities and support, employment, support services based around your needs and not the service provider/service provider staff.
- "I can only work part-time because I only have funding for so many hours per week employment support. Heaven forbid I should have an early meeting because my carers don't arrive before 7am. And how would I get to bed past 10pm without my Mum?"
- Public Housing and/or no deposit/no interest loans so people can buy their own homes (we know there are several schemes across the world that do this)
- Long term supported accommodation for those who, for whatever reason, will not be able to live independently. However by this we do not mean mini institutions but family,-like

homes where people are well matched, live together in harmony, get their support needs met, are as actively involved as possible both within their home and into the community and get to choose (or their family gets to choose) the people who provide the service – management and hands-on.

- DCV respectfully suggests that where there has been a life-long/long-term disability that support should continue past the age of 65. Either that or some serious adjustments need to be made to the aged care system which, in our experience, does not cope well with people with a disability.
- "I'm looking forward to being 65, because my disability will be replaced by old age, and maybe I'll be able to replace by wheelchair with a wheelie-walker" said one of our cheekier members, somewhat tongue-in-cheek. But the point was well taken. She will still need disability supports after 65.
- More therapists of all kinds, more trainers, more support staff, more advocates, more planning support
- Government Departments need to look at 3 areas and fund these areas far better than currently:
- Innovation – there's been some wonderful examples of innovation over the years. Services get seed funding and then (no matter how good it is) funding ends, expected to be sustainable (service delivery is never sustainable- although perhaps if we had more self managed packages this would help) or just end so they can fund another great idea. This has to stop. If it works and people want it then fund it.
- Information services – the system cannot expect people to be actively engaged in determining their needs and the services that they want to use if they don't have access to information. Information services like DCV receive nominal funding (we get $37,000 recurrent a year –with only CPI increases over 10 years despite a 5 fold increase in membership over the last 7 years and 700,000 hits a year to our website. And please don't forget that many people with a disability and families do not have access to email and web based information (due to both cost, literacy and language issues)
- Training, empowerment and advocacy. People cannot be expected to manage their packages, negotiate their support needs and self advocate/advocate for the person they support without the training and support they need. The reality is that many people with a disability have been severely disadvantaged in terms of education but also disempowered by a system that makes decisions for them i.e., disempowers. Preferably there should be funding for advocacy support if needed and services like DCV should be funded, expanded and nurtured (especially where they are grass roots)
- DCV members thought that the outer Metro regions probably have more in common with Regional/rural Australia than they do the inner city areas (except numbers of people). So we believe that making it easier for people to use their natural/community supports in a professional rather than volunteer capacity makes sense (pay your sister, your neighbour, your friend)
- Realistic carer payments (equivalent to the weekly wage that a paid carer would get) plus superannuation for carers/families who opt to reduce the cost to community (and adding quality of life to the person they care for) to   those who choose to remain at home to undertake the caring. Reduction/removal of the requirements for carers of children with a

disability to seek paid work. More support and flexibility (including extra child care rebates) where carers choose to return to the workforce.

Funding

DCV members believe that this scheme must be supported by the entire community through a tax-payer funded system similar to Medicare. No-one in Australia believes that it is OK to deny a person the right to medical services. No-one should been prevented from accessing disability supports either. DCV members consistently made the observation that disability can “hit” anyone, anytime – a family member born with a disability, a trauma, an illness, a stroke/heart attack. And also that someone famous once said that the quality of a society can be judged by the way it treats the most vulnerable. This is a community responsibility, which requires a community response.

Australia is a signatory to the UN Convention about the Rights of People with a Disability (plus children, refugees etc). As a community we should be enshrining those rights in legislation – no matter the cost. As a community we need to find the money to treat people the way we ourselves or someone we love would like to be treated

There is no doubt that a scheme of this kind is going to be more expensive than the current system-especially in the short-term as we start to uncover the real level of unmet need. Government Departments have stopped recording anything except crisis need (how we often ask can they plan when they don’t know what they are planning for?) and there are huge levels of “under-met” need

> “I very carefully planned what I wanted my support package to fund. Before the planner even looked at what was in it she said it was too expensive. So I struggled and cut it by 25%. It was hard deciding what to leave in and what to take out. But I did it. When it came back it had been cut by half again. I was at my wits end. There went quality of life and choices for J. All we could afford was the major areas of need and only a bit of them”.

However we believe that by reducing the amount of money it costs to “gate-keep”, to “reinvent the wheel”, to “regurgitate the paperwork” the costs of the schemes administration could be minimised drastically.

We also believe if you cut the infighting and “middle-men” costs of passing funding from Commonwealth, to State, to Department, to region, to service provider, to eventually service user you would save perhaps 60% of costs (sadly at the expense of all those now unneeded bureaucrats and accountants)

If you empower and train people to be more independent you will not need hours of paid planners to help people decide what they want. If you provide adequate information and advocacy services people will need little support to identify their support needs and cost them. This reduces bureaucratic costs and reliance on highly paid professional staff

We also believe that if early intervention services, education, post school training, employment support etc were better then more people with a disability would be in the workforce. Thus changing them from receivers of welfare payments to tax payers (or at least a mix of the two)

We also believe that by having better early intervention services, education, post school training, employment support etc then people would be more skilled, more independent and therefore less likely to be dependent on paid support services (or at least using different ones)

We also believe if carers were better supported, if services changed from the current baby-sitting/school based model then more carers would be able to enter the workforce, afford to pay for some of their own supports and also contribute to superannuation over time

“My husband and I both work part-time because our caring responsibilities don’t fit in with a day program that finishes at 3pm and has school terms- and he’s 24 now”

Some members thought that there could be some form of reasonably priced. (maybe government supported) insurance scheme (similar to Medibank, HBA or life insurance) that people could pay into in a similar way to what we have with TAC (Traffic Accidents), Workcover or life insurance.

Several members were extremely strong that this scheme should work in conjunction with current models such as TAC and Workcover and should not negate litigation and compensation.

Remove the paper work barriers to people with a disability/carers undertaking part-time and casual work – people said it wasn't worth the effort. They forgot the importance of social interaction, the valued status of employment and the difference between being a contributor to community rather than a welfare recipient.

Of course many of these benefits will not come straight away. And there would be costs now that will not reap benefits for years to come e.g. training in, investing in and employing more therapists, assessment professionals and other early intervention practitioners will not achieve tangible outcomes for many years. It's going to be 20 + years before a child born today will become a tax payer. So Governments of all persuasions have to turn their way of thinking completely upside down and stop thinking in terms of each election period but in terms of generations. It's too late for today's carers in their 50's, 60's, 70's and 80's to become self-funded retirees but like governments past looked at superannuation as a long-term plan so this should be.

While we believe that everyone should have their needs met we don't assume this means the bucket is bottom-less. We think it's not unreasonable to ask people to contribute to the cost of things if they want "the Rolls Royce" version (provided of course there is a suitable alternative). Provisions to "pay-off" an item, a wage or insurance would help

Another idea arising from DCV discussions that DCV felt really could help defray some of the costs was a genuine pay back/trade-in/second hand equipment scheme – so much of this stuff is expensive so why not try to utilise it to full advantage e.g. if the child has outgrown the wheelchair try to find another child it will fit or re-fit it (now there's a social enterprise to provide employment and reduce costs).

And of course if all buildings were built to universally accessible standards then the cost of home and office renovation would be minimal.

Other points to consider (not quite sure where these go)

The scheme in some form has already started with the welcome move to self managed funding. But this is fraught - so difficult to be "approved", so much over-accountability for the money and concern that people will rort it or spend it all at once and have nothing leftover.

There are many organisational members of DCV (and their very professional, committed, passionate staff) who are trying to do things differently. This is difficult because the funding doesn't match the vision. When funding continues to be based on group activities it is hard to do one:one/more individualised.

"I asked for my son to do horse-riding at his day placement. It took 6 months. They had to find a group to do this as it was too expensive and the logistics too difficult to do it for just 1 person"

There are some fantastic pockets of service delivery but they depend on having funding, having a vision, having the support of the Department. Many of them rely on huge numbers of volunteers- all need training and supporting. We could not put a price on their contribution.

There is already a genuine crisis around support staff. There's not enough of them, they are basically the baby-boomers heading for retirement (or increasingly in our area international students with all the language, cultural and career issues that comes with this, not to mention they are looking for a well paid career and see this only as an entry into the workforce). There are hardly any young people entering the field – it's just not seen as a career option. Those that enter don't last – why would you when you get paid the minimum wage for such a responsible job, doing some incredibly professional tasks with people who (might) beat you up, work long shifts across 24/7 etc.

> "I've been working in disability for 30 years, have 2 higher degrees and earn less than I would working in the local supermarket. To make things worse if I worked for a government department rather than a Not-for-profit agency my base rate would go up $8 an hour."

As stated above the ever increasing reliance on web-based information is an issue for large sections of the community and advocacy/information services are scarce, under-resourced and only doing a percentage of the empowering work that will be needed.

Many of the DCV members will put in their own submissions, however many more are happy to give their views and contribution and let DCV collate it into one document. A copy of this submission will be sent to everyone of our members this week by mail or email.

Once again we would like to commend those people who had the vision to put forward this proposal, to those who have the strength, passion and integrity to push it along and not let a good but excruciatingly difficult to implement idea die and to respectfully beg all concerned not to put this in to the "too hard basket".

If you have any questions or would like clarification on any of the points above please do not hesitate to contact me on03 96877066, emailing helen.dcv@annecto.org.au or the DCV Chair on 03 9749 6949 or emailing chair.dcv@annecto.org.au

Yours sincerely

Helen Adams
Executive Officer, disAbility connections (Victoria)