

Submission to Productivity Commission on a Long Term Disability Care and Support Scheme
by
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Personal Background

I am a person with an acquired disability from a motor vehicle accident in 1989. I am a C6/7 quadriplegic and I use a manual wheelchair at all times. I also recently realised that I am a person with a severe and profound disability, although I have very rarely thought of myself as such. I am also a wife and mother of two young children.

I was lucky enough that when I had my motor vehicle accident, I received a lump sum compensation payout to pay for my care and support. I have also been lucky enough that my payout has lasted for 20 years and is still able to provide me with the income I need to pay for my support. This is because I had good advice from my parents and a trustworthy accountant. Over the years I have made some bad choices from bad financial advice, but I also have diverse investments. I have always worked on a budget of what my monthly income needs to be for support and ensured that I could stick to it. This is something I had to learn to do, and would have been made easier by have a sum each year rather than the lump sum.

I currently employ my own support workers. Over the years I have sometimes used service providers, and some times employed my own support workers, and sometimes done a combination. This has been dependent upon my situation, and time. I require and pay for approximately 45 to 50 hours a week of support. When I lived on my own this support was provided solely by support workers, and now my husband provides approximately 10 hours a week of support.

Due to having my own funding that I have been able to manage and control, I have had the flexibility to employ a nanny when I needed it and take support workers with me on holiday. I have got the wheelchair and cushion I need and been able to get other supplies as and when I need them. Without this flexibility, I would not have met my husband, nor had the support to have children.

After my accident I returned to university, and completed a degree in social work. Since 1993 I have worked in the disability sector in Western Australia and Victoria as an advocate, case manager and policy officer.

Eligibility

Who gets services

This is always an area of contention because resource allocation is an issue. The question of who gets services has a number of elements which impact on how the question is answered and will impact on future approaches.

Whose voice is being heard by the resource allocators? Currently the voice of carers is very strong. There is a lot of media coverage on carers and carer issues. This has been picked up by government with initiatives such as the carers bonus and increases to respite programs. This is a legitimate area of need, however the group of people with disabilities who need support and face barriers to participation is much bigger than just the group with carers yet their voice is not so strong. There are also new voices in the disability sector (HIV/AIDS).

At a program level it is often stated by workers that those who prove they are suffering and disadvantaged the most will receive services. Often this is because of limited resources and restrictions on eligibility criteria or program numbers. Eligibility should not be based on who has the loudest voice.

How services and definitions are framed can have an impact on who gets service.

The classic example is that disability services are for those aged under 65. Currently many people with disability access age related services to top up their support (such as from HACC and things like meals on wheels). In the future those aged over 65 with disability may be tapping in to disability services for their support. Also disability doesn't stop at 65 and with life expectancy increasing, people with disability who are ageing will be trying to access two systems. I believe it is very important that people with disability who get long term funding as part of a new scheme retain funding for their disability support when they are over 65, as well as being able to access appropriate aged care services where required.

In many states, including WA, mental illness or psychiatric disability is still separate, in practice if not in the written definition. It has been difficult to separate the supports for acute and chronic needs in episodic illness. This has often lead to people with multiple disabilities which include a psychiatric disability getting no support for that need, or no support for their other disability. There are also new health areas falling under disability such as HIV/AIDS, Autism Spectrum Disorder including Asperger's Syndrome, and people with allergies and chemical trauma. Need for support must be the underlying factor in who gets services.

The World Health Organisation (WHO) bio-psycho-social model of disability is used by the Australian Institute of Health and Welfare when defining disability. The WHO definition is the International Classification on Functioning, Disability and Health (ICF) which 'synthesises what is true in the medical and social models of disability' (WHO 2002). The ICF measures functioning and health in a matrix which incorporates environmental factors and the ability to participate meaningfully in society. It is seen as an important tool for data and analysis in the paradigm shift from a medical model of disability to a bio-psycho-social model of human functioning (WHO 2002). It is a model which defines disability in ways which include environmental factors and the impact of impairment on participation, whereas the definitions in legislation aim to prescribe disability to an impairment. This definition should be used in developing eligibility and analysing future need.

Multiple Services systems. In Australia a person with disability could have a compensation payout and purchase private services for a high hourly rate, while people reliant on state funding can get services at a different rate with restrictions on how much. Then there are federally funded services such as Home and Community Care and Department of Veteran Affairs who pay another hourly rate with different restrictions on funds. Most programs also have restriction on access to people already receiving services elsewhere. Those with high needs can often access multiple services but must provide multiple applications and accountability. WA has the Combined Application Process which assists with state funded services.

These multiple systems often require service providers to have multiple accounting systems dependent on who is paying and what rate is being charged. There are also incidences of people with disability who are born with their disability stating that they wish they had acquired their disability through an accident to get compensation so they could

afford more support. While those with compensation payouts wonder why they pay higher rates for all services.

Where you live. For those who live in remote and rural areas there is often little choice or options for what service you might get, if you can even get services. Family and informal support networks can be much stronger in smaller communities, but still may not meet the needs of the person with disability or the respite needs of carers.

Challenging behaviour and high support needs. There are groups within the broad group of people with disability who often are quite limited in the services they get because they are seen as being too high maintenance or challenging. Many of the websites on person centred planning and direct payments give examples of people whose behaviour changed when they had more control over their lives, or when the planning process highlighted their abilities and focused support on enabling those abilities. Further research and data gathering in this area is needed to know that a changing service system can bring this group along and not have a sub class of people who remain further disadvantaged. However there are examples highlighted on the websites of In Control Australia and In Control in the UK <http://www.incontrol.org.au> and <http://www.in-control.org.uk> .

Eligibility Criteria

Having eligibility based on need is as simple, and as difficult as asking people what support they need instead of what diagnoses they have. Need is contextual. This is why it is very difficult to say a certain group has a higher need than another group. I think that obviously the most basic of needs must of course be a priority, so if someone cannot feed themselves or care for their own toileting then those needs must come first. But those needs could be the needs of someone with an intellectual disability or autism, and the same needs may be the needs of someone with a physical disability. The reasons for those needs are different and the type of support needed to meet those needs may be different. The context of location and informal support also changes need. Some one may have no family support, or a family or carer who is burnt out, ageing or unable to provide support. Someone like myself may not want their spouse or family to be providing all the support. Other people may have carers who want to provide support. The capacity and willingness of a carer to provide support is part of the context.

Keep eligibility simple, and worry about how much funding people get, to get the right support, in the assessment process which takes context into account. So anyone who needs support becomes eligible but how much funding or support they get is based on an assessment process.

Simple eligibility criteria may be:

- Has a disability
- Need support
- Australian citizen or permanent resident.

Being eligible may not mean you get funding for direct support if you don't need it, but may give you eligibility to information, planning services, subsidies for medication and transport and other ancillary benefits.

First point of contact

The Local Area Coordinator (LAC) program in WA is a good example of a first point of contact that is a local information/referral point for people with disability and families. However the role of LAC's is sometimes so broad it is unclear what they do. Their main role is providing a service coordinator and linkage role to people with disability and families

that are eligible for services and so those that need a small amount of support/information may miss out. Due to this the Disability Services Commission WA funded 'Disability First Stop', which is run through People With Disability WA. The idea of 'Disability First Stop' (DFS) as a place to get information/referral for anyone with a newly diagnosed disability is very useful. For it to work more broadly it would need more resources, better promotion, and have links from the specialist hospital areas to the DFS. It would also need to be for anyone wanting information for disability support and should be able to refer people to LAC's/facilitators/case managers for assistance with doing an assessment for funding and/or planning.

The Commonwealth Carer Respite Centres also currently provide a single information/referral point for respite in each state, and in some states like Victoria they also provide all the information and referral for State based respite services. I believe respite is really family support and should not be a separate system. However this single point for information/referral is another model that could be looked at with DFS.

Assessment for funding

Needs are contextual, so I keep coming back to some form of self-assessment that is simple and includes the measure of informal support willing and available. Assessment systems should be simple to work out a funding band followed by the opportunity for support to do the planning of what a person uses the funding for.

The Resource Allocation System used in the UK utilises a self assessment with funding bands that is tailored to the amount of resources available. For more specific information on how the RAS works see Attachment 1 from In Control UK.

In the first stages of individualised funding in Victoria and in the Community Living Initiative in WA, person centred planning is done as the step to work out how much funding a person should get. So a person and/or their family, with or without support from a case manager/facilitator develops goals, strategies, actions, and a detailed care plan of the support they need to achieve their goals with a funding proposal. Some criticism of this approach has been that people need to know what band of funding they have so as to make realistic plans. Also my experience was that good support from a trained facilitator/case manager who understands person-centred planning made a big difference in the quality of plans. A funding proposal of how funds will be spent is still essential as it forms the basis of a budget for the individual or family, however good planning for people with only minimal support needs may provide for a plan that requires no or very little funding.

Traditional case management or case based approaches can be empowering and flexible in the right systems but can also be as equally dis-empowering when used to control and limit peoples choices.

Elements of traditional case management

A case management role is often used to assist people with disabilities in accessing services and support. The following elements are those aspects of traditional case management which may serve to continue institutional practices and systems and in doing so limit and de-value people with disability and their families. Many case managers and professionals in similar roles would see themselves as facilitators or brokers yet still retain some of these elements in their work.

- role is time limited such as a three month period or time limited such as 1 hour a fortnight to meet competing demands from new referrals and other clients.

- the role involves assessment of eligibility for services and acts as a 'gatekeeper' for the service system and resources available.
- the majority of referrals or placements for support are to existing and disability specific services and providers
- options for people with disability and their families are censored and narrowed down by the case manager

(Williams 2007)

Person centred planning is one of the main tools used for creating independent living. It is a process of life planning for individuals, based around the principles of inclusion and the social model of disability. In person centred planning the process, as well as the product, is owned and controlled by the person (and sometimes their closest family and friends) (Circles Network 2008). Person-centred planning involves the development of a "toolbox" of methods and resources that enable people with disability to choose their own pathways to success. Planners or facilitators help them to figure out where they want to go and how best to get there (Cornell University Person Centred Planning Education Site 2008).

Elements of person centred planning

- The person is at the centre
 - The person is consulted throughout the planning process
 - the person chooses who to involve in the process
 - The person chooses the setting and timing of meetings
- Family members and friends are partners in planning
- The plan reflects what's important to the person, their capacities and the support they require
 - There is a shared understanding that the person is the expert
- The plan results in actions that are about life, not just services, and reflects what is possible, not just what is available
- The plan results in ongoing listening learning and further action

(Sanderson 2000)

There are many tools of person centred planning which are used, the most notable being Essential Lifestyle Planning, Personal Futures Planning, MAPS and PATH. An element in all of these is the expectation that a planner will assist in putting the plan together. The elements of planning and facilitation are:

- A commitment to know and seek to understand
- A conscious resolve to be of genuine service
- An openness to being guided by the person
- A willingness to struggle for difficult goals
- Flexibility, creativity, and openness to trying what might be possible
- A willingness to enhance the humanity and dignity of the person
- To look for the good in people and help to bring it out
- To have done planning for yourself to understand the process

(Cornell University Person Centred Planning Education Site 2008)

In person centred planning there is an assumption that the planner will assist the person with disability to look outside their comfort zone and bring options and information to the planning process that is outside of the traditional disability support services. It is a tool for inclusion and supported living mostly used with people with intellectual disabilities, but can be used by anyone.

A case manager/ facilitator such as the Local Area Coordinators (LAC's) here in WA could assist with assessment processes to get people funding and play a continuing service coordination/case management role if the individual/family wish. Many people who acquire

disabilities such as ABI find a case manager type person who follows through with them from hospital is really useful. Others, such as those with physical disabilities may or may not need a case manager until such time as they realise they require some support. This is where things like Disability First Stop can pick up those people who fall through the gap of hospital referrals.

Newly acquired disabilities need a more comprehensive model of assessment and preliminary support with changed life circumstances and the transition from hospital to community. Maybe a multidisciplinary team similar to the Aged Care Assessment Team could assist, but there would need to be some follow through with a case manager to actively provide planning and coordination of services while people get back to organising their lives.

How funding is distributed and what gets funded

This is an opportunity for the system to have funding for direct support to be all individualised with people with disability and families in control. The Victorian approach to individualised funding and support is more comprehensive than WA in terms of flexibility of what the funding can be used for and the options available for managing funding, however there also issues with people needing to have person centred plans done by specific facilitators.

In WA we are part way there because all our funding is disaggregated. But I think options for how we manage funding is limited and flexibility of what we can use funding for is limited.

For individuals and families to be in control, I believe all funding for direct support needs should be individualised (disaggregated – everyone knows how much they have and can take it with them and use it to purchase what they need, not just specific types of support) with a range of management options e.g.

- Funding going directly to the person with a disability
- Funding is managed on the person's behalf by a trusted other such as a family member.
- Funding going to a micro-board or 'circle of support' who manage the budget and funding with constant checking of the plan and decisions with the person.
- Funding going to a financial intermediary (FI), a bit like a bank, where the person (or family member on behalf of a person) has control of the things that are purchased, but the invoices are sent to the FI who pays them and sends monthly statements to the person.
- Funding going direct to the service provider you choose. This is a bit like many current systems, but planning and control of decisions is squarely with the person and family.
- Funding going to a case manager/broker who works with the person and/or family to develop and implement their plan, purchase services and undertake accountability.

The key point is that decision-making is done by the person living with disability (and those closest to them where that is appropriate) with as little or as much support as is needed. This model also incorporates the option for people to employ their own support workers,

use an agency to do payroll (insurance, tax, etc.), or negotiate a shared management model with a service provider.

I think there needs to be a lot less rules about what you can use funding for and more emphasis on just assisting people and/or families to develop good plans. There should be a reduction in the rules around what funding can purchase to three simple rules for all self-directed funding;

- nothing illegal
- no gambling
- funding must be to meet the needs of the person with disability as articulated in the goals of their plan.

When people talk about Individualised Funding or person centred and family centred planning and services, they are talking about a change in the culture of providing services. Some of that cultural change can only happen by service providers and government making the effort to do it. For me an important part of that cultural change is about giving power and control to people with disability and families. Some people put forward a model where no funding for providing direct services goes to service providers, it has to go to the person directly, or the person directs spending through a broker or case manager or FI.

One of the biggest cultural changes that needs to happen is a commitment to change the support system to assume a person with disability has capacity and ability until proven otherwise, and then support to build the capacity of people with disability and families put in place. There are many tools which can facilitate this approach such as person-centred planning, circles of support and micro-boards. There is also the need for what I term 'indirect' supports as mentioned further along in this submission.

Certainly there needs to be redevelopment of the service system to allow for a variety of service responses for people with disability which would include;

- Making any disability support funding received directly or controlled directly through a broker exempt from income or other taxes, and exempt from a persons eligibility to receive income support (such as DSP, Newstart etc.);
- Allowing contract work in the disability sector even if it is strictly in violation of tax office rules;
- Allowing for the development of support worker insurance models that people employing their own workers can use.
- Assisting disability specialist providers to change to become connected to mainstream services and to have up to date business practices;
- Supporting people with disability and families to form co-operatives and start their own services;
- Support and education on GST, insurance etc. to ensure people purchasing directly are not getting charged things they shouldn't be, and are supported to find different ways of addressing these issues such as collective work cover insurance;
- Better connection and education of people with disability about State and Federal Fair Trading Acts in regards to using that legislation to check quality of services and contracts in disability services.

Models of independent and supported living sometimes called self-directed funding

The key elements of independent and supported living is that control is with people with disability and their families, planning for support is whole of life and person centred, and there is transparency and flexibility in funding. This approach is not a model and in fact

does not agree with a model driven system but rather systems that are transparent, flexible and working to meet the diverse and individual needs of people with disability. Often this is about giving people with disability self-determination.

Elements of self-determination (self-managed care, individual control, supported living)

- Freedom, for people with disability to have control and use of their funds to build a life rather than have purchased for them a pre-determined program, with freedom of choice in how they use their funds.
- Authority, so people with disability really do carry meaningful control over their life and are respected as having that control.
- Support, from both formal and informal support networks which enable participation in the life of the persons community.
- Responsibility, where people living with disability are expected to assume responsibility for not being passive recipients of support but for also contributing something to their communities, like any other citizen.
- The expert is the person with disability and their family.
- Separating the provision of housing and support to give people flexibility to change and move.
- Key emphasis is on relationship building.

(Kinsella 2001) (Williams 2007)

Some of the examples of models or approaches which are currently popular and fall under the philosophy of independent living are more like tools which can be used to achieve community inclusion and self determination. Sometimes these tools when used in isolation or without the culture of the underlying philosophies and principles of inclusion and self-determination, can become as dis-empowering and inflexible as other institutional methods (Williams 2007).

The term Self-directed Funding is often interchangeable with individualised Funding and usually refers to a range of ways that the person with disability can know how much funding they will get and control what it is used to purchase.

Elements of individualised funding

- The person knows how much funding they will get
- The person has genuine control of the funding
- The person has a plan which they have developed
- The person receives support to comply with accountability

(Williams 2007)

The Direct Payments program in the UK with the In Control method of support and control is a great example of self-directed funding. In particular they have developed a framework for Individualised Budgets which means all people with disabilities can have individualised funding, self-directed support and ultimately independent living. They have worked in partnership with a number of councils in the UK and implemented the framework successfully with people with disability. The things which make it work are the support from Centres for Independent Living and the very small number of rules that are set to limit peoples purchasing. The accountability is simple and once a year and comes back to the persons plan that they have developed. This is a shift in power which puts responsibility and accountability back to the person with a disability, as well as choice and control. (Kinsella 2000)

In Victoria there has been a project using similar principles called the Direct Payments Project. This is a project which trialled 10 people with disability and /or family receiving

their funding in monthly payments, with minor restriction on what could be purchased but assisting people to develop a person centred plan to guide their spending. The project was extremely successful for participants in terms of flexibility, control and choice and it is now being expanded to 100 people.

I worked on the transition to individual support in Victoria and the Direct Payments Project and can tell you that 3 monthly auditing for accountability of people receiving payments directly was too much, and a waste of resources. It took at least a day per person to go through the papers ask questions and compare expenditure to plans and bank accounts. The Direct Payments project aim was that long term there would be annual acquittal, random 10% audits and more support in early stages for those new to the program. I believe this is what has occurred and more information can be gained from http://www.dhs.vic.gov.au/disability/improving_supports/direct_payments_project

The flexibility that people require means that there must be a range of options for people with disability and families to manage their funding and support as previously mentioned. Some examples of organisations which have specialised in different support mechanisms for families such as micro-boards and circles of support are:

- KeyRing Living Support Networks - People supported by KeyRing live in ordinary homes within walking distance of each other in a community. A community living worker who is similar to a case manager or broker, builds supports around each individual in this community.
- Vela Micro-boards -A Vela Micro-board is formed when a small group (micro) of committed family and friends join together with a person with challenges to create a non-profit society (board). Together this small group of people address the person's planning and support needs in an empowering and customised fashion. A Vela Micro-board comes out of the person centred planning philosophy and is created for the sole support of one individual. The process must be focused on the dreams and wishes of the person for whom the board is being created. All Micro-board members must be in a close, voluntary, and committed relationship with the person for whom the board is being created. These close relationships are the foundation of the board and must be honoured above all other activities.
- Circles Network - Circles Network is a UK voluntary organisation based around the key principles of Inclusion and Person Centred Planning approaches. Circles Network provides individualised personal support using the tools of Person Centred Planning to facilitate inclusion in the community, principally through the setting up of Circles of Support and through individual projects for specific areas of need.

In the UK and elsewhere it has been shown that people with disability and their families are usually more cost effective in their purchasing when they are in control, yet other resources need to be developed to support and educate people with disability and their families in the role of purchaser (Williams 2007). This means at best it would cost governments less and at worse it would cost the same.

The following principles must be the base criteria for funding and service delivery for it to be self-directed funding;

Principles

1. Independent Living

I can get the support I need to be an independent citizen.

2. Individual Budget

I know how much money I can use for my support.

3. Self-Determination

I have the authority, support or representation to make my own decisions.

4. Accessibility

I can understand the rules and systems and am able to get help easily.

5. Flexible Funding

I can use my money flexibly and creatively.

6. Accountability

I should tell people how I used my money and anything I've learnt.

7. Capacity

My capacity is assumed, and I can also get information and support to build my vision of what is possible in my life

Independent and supported living examples

Supported living website, Information site by Family Advocacy and Multicultural Disability Advocacy Association in NSW

<http://www.supportedliving.org.au/resources/index.html>

One by One, Family governed group in Victoria

http://www.onebyone.org.au/index.php?option=com_frontpage&Itemid=1

Homes West, Queensland

<http://www.homeswest.org.au/>

My Place, WA

<http://www.myplace.org.au/welcome/index.html>

Community Living Project, SA

<http://www.clp-sa.org.au/>

PLAN Canada

<http://www.plan.ca/homepage.php>

California Supported Living Network

http://www.supportedliving.com/supported_living.html

KeyRing Living Support Network

http://www.keyring.org/site/keyring_splash.php

Paradigm UK

<http://www.paradigm-uk.org/>

In Control UK

<http://www.in-control.org.uk/>

Vela Microboards

http://www.microboard.org/what_is_vela.htm

Circles Network

<http://www.circlesnetwork.org.uk/>

Victorian Department of Human Services (DHS) (2008) Direct Payments Project

Indirect support systems

I think a major part of the issue for cultural change and changing power dynamics is the need for some capacity building of individuals, families, service providers and the community; and a need for complimentary support.

What I mean by capacity building is education, training etc. in how to manage funding, how to make complaints, and how to influence and engage in policy advice and decisions. It is also promotion of rights and the involvement of mainstream entities such as consumer affairs educating people about smart purchasing and contracts. It is about the availability of information, advocacy, seed grants, and updating of technology and systems for service providers. For the community it is about funding and support of local government and other government departments to provide accessible services and facilities and information.

By complimentary support I mean stuff like community development workers in local government that can support systemically the work of people like Local Area Coordinator's. Bringing consumer affairs people on board with disability rights, and community education campaigns.

Any new scheme which replaces current systems must have a commitment to provide funding and support for capacity building and community development. This would require;

- Disability awareness and community education campaigns at national and local levels that involve people with disabilities in planning, developing and implementing the campaigns. With culturally aware campaigns among different communities.
- Community development workers at local community levels to work with mainstream organisations on inclusion of people with disability, and who also work with disability specialist services to advise them on becoming more inclusive in their practice; for example cluster housing including private rentals, alternative to employment centres running activities for the mainstream local community.
- Funding for people with disability to have the support to attend mainstream corporate and community leadership programs and a commitment to their being places made available.
- Innovation seeding grants for local initiatives that involve people with disability being part of the community, and are planned and developed by people with disability.
- Support and training made available for people with disability on citizenship, navigating the system, becoming the boss of their supports and being in control.

It also means a commitment to building the capacity of the disability advocacy and support sector to empower people with disability. This would include funding for training, board capacity building, and support to employ people with disability.

Examples of capacity building that could be funded in a new system are:

- In the UK the Centres for Independent Living provide advice, support and information on employing support workers directly, planning and budgeting, equipment etc. E.g. <http://www.icil.info/>
- 'Becoming the Boss' is a training course to empower individuals and families in Victoria run by Action for Community Living.
- 'Developing Active Citizens' is a similar course run by People with Disability WA.
- 'Leadership Plus' is a Victorian leadership program for people with disabilities.

- The Self-advocacy Resource Unit (SARU) is a Victorian state government funded initiative to support self-advocacy through resources, education and training (usually for people with cognitive impairments such as intellectual disability and ABI).

Community inclusion is not about people with disability doing activities in a community setting or living in a house in the suburbs. When community inclusion is envisioned it is about people with disability 'Being of the community' which means:

- People know you, you may be a regular at the local supermarket or coffee shop.
- You feel safe and that you are in familiar surroundings.
- You have reciprocal relationships with others.
- There is a sense of belonging.
- You are valued and have a sense of self-worth
- You have social connections and networks in the community.
- You are asked to participate and work together with others in the community.
- Your views are listened to.

(De Hoedt 2002)

Elements of community inclusion

Community inclusion is seen as part of the paradigm shift in the disability sector, and the practice of community inclusion has the following key elements:

- Relationship building and relationship development skills are facilitated.
- Awareness of disability and community education, particularly to generic services and businesses.
- Focus on people with disabilities as individuals with lifestyle choices, interests and desires.
- People with disability have life goals they set, change and aspire to with support from formal and informal networks in the community.
- People with disability actively participating in their lives, e.g. shopping, cooking, cleaning, paying bills etc.
- People with disability supported (if needed) to actively participate in their community e.g. vote, take part in council reference groups or other local groups such as dog walking etc.

(De Hoedt 2002)(Kennedy, Sanderson and Wilson 2002)

Community development and education is seen as a key role in promoting social inclusion. There are many examples of specific programs and initiatives which do this. Successful projects include:

- Bar None – a project in Victoria which involved training community newspaper journalists in how to portray people with disability and disability issues, while giving them stories from people with disability nominated for doing things in their local communities. This was done by the Victorian Office of Disability. <http://www.youtube.com/watch?v=LWnd760R7ok>
- Count Us In – WA broad community education campaign and information for community.
- “Talk” Disability Rights Commission UK and others – In the UK from 2006 the Disability Rights Commission did a series of advertisements that are on Youtube turning the experience of people with disability in employment on its head. The newer Equal Opportunity and Human Rights Commission in the UK has followed up with a series on their website called Equally Different were a range of well known and ordinary people from different backgrounds (CALD, disabled, war veteran) tell

why they are different.

- Creature Discomforts – Leonard Cheshire Disability Rights in the UK have a series of commercials done by the well known Aardman Animations studio, which use the stories of real people with disability with animated animals.

More long term community development work is also done by the Local Area Coordinators in WA, where they build connections over time with the area they work in. A similar approach is in Victoria although the workers are located in local government and do not do any individual or disability services work, but only focus on community mapping, and community projects and connections which include people with disability in mainstream activities. These are called the Metro Access and Rural Access workers.

Community Engagement examples

NSW Don't Dis my Ability campaign

<http://www.internationaldayofpeoplewithadisability.com.au/>

UK Leonard Cheshire Disability Rights, Creature Discomforts Campaign

<http://www.creaturediscomforts.org/>

UK Disability Rights Commission Youtube commercials

<http://www.youtube.com/user/DisabilityRightsComm>

UK Equal Opportunity and Human Rights Commission Equally Different Campaign

<http://www.equalityhumanrights.com/en/projects/equallydifferent/Pages/EquallyDifferent.aspx>

Victorian Department of Human Services, Metroaccess and Ruralaccess

http://www.dhs.vic.gov.au/disability/building_better_communities/ruralaccess_and_metroaccess

WA Disability Services Commission, Count Us In

<http://www.disability.wa.gov.au/DSC:STANDARD:1189358996:pc=L3>

This stuff all requires people and resources... funding as well and should be explicitly part of any new model of a funding system.

Participation, Governance and Policy/Service Development

Participation and involvement of people with disability and families is a cornerstone element for me of any model working. Participation in decision making at all levels including policy development in particular. Whatever model you may think is best we have an obligation in Australia as a signatory to the UNCRPD to ensure the articles and the rights in the convention are being upheld.

Using self-assessment in conjunction with case managers involves people with disability and families in decision making on what support they need. Person centred planning must involve people with disability and can be the person or family doing it themselves. Involvement of people with disability could be through evaluation and monitoring of systems. Independent monitors in WA are being recruited from among people with disability and families for the Quality Monitoring Framework.

Any new policy or program should be done in consultation with people with disability. The

development of the Direct Payments Project in Victoria used an Action Learning approach with 10 participants which was extremely successful.

Regular feedback on policy and practice through system reviews, open meetings, conferences of people with disability and other such mechanisms are important indicators of a healthy system. Of course this means that bureaucracy must listen and act on feedback also.

Encouraging participation also means a commitment to changing language and providing support and access such as;

- People with disability and funding allocations should not be given as 'places' but rather as 'support packages'.
- 'Respite' changed to family support or some other term that encompasses the idea that support is being given which is meaningful for the person with disability as well as providing support for carers. Currently the term 'respite' excludes the person with the disability from any choice or control of the support received.
- Use of plain language as a matter of course not as a special request.
- Fund support for participation in conferences, advisory groups etc.
- Ensure technology for access is available.

People with disability should be part of a governing body that looks at developing policies, principles and monitoring and evaluation. Like the Disability Services Commission WA Board which is legislated to manage the Disability Services Commission WA, the governance of this scheme could include a Board which includes people with disability, family members and service providers from all states.
<http://www.disability.wa.gov.au/dsc.html>

This scheme would fall under the National Disability Strategy which should also have the involvement of the peak bodies representing people with disability in Australia

Funding

All disability support specific funding (including all current National Disability Agreement categories, and allowances and programs such as Mobility Allowance and the Continence Aids Payment Scheme and aids and equipment, but apart from the DSP and advocacy and indirect supports) at state and commonwealth levels should be allocated via a Resource Allocation System that is fair, equitable and consistent across Australia, and gives a dollar figure to people with support needs. Such a tool could factor in extra funds dependant on location (remote or rural areas with extra funds to acknowledge transport costs and higher service costs).

Money from tax needs to be pooled with money from insurance models to get rid of the multiple systems, or have one system for distribution of funds, monitoring etc. even if behind the scenes there are two or three buckets. Of course the varying state insurance commissions would still need to deal with claims for 'grief and loss' and 'loss of income' and such, but all support funding should come under the one scheme.

Money for advocacy, complaints services like ombudsmen, community development (such as the metro access/rural access workers in VIC) and capacity building could then come from the one bucket budget.

I am concerned about questions of means testing and co-payments which need a lot of research into the effect on different people given their support costs, location etc. Also

concerned about questions of private contributions and what exactly that means. A special disability trust may only cover some aspects of a persons needs. Private contributions should not mean a scheme like superannuation contributions, where you only get what you can contribute as this would set up a two tier system again.

Workforce issues

In redeveloping the system there must be a strategy with actions developed to address the many workforce issues in the disability sector. This should include;

- Better pay and conditions for support workers and advocates.
- Redefining the many and varied roles support workers take on, as some require high level skills, some manual skills etc. and all require commitment to inclusion.
- Allowing support workers to be contractors, not necessarily work through an agency.
- Provide career opportunities in the disability sector.
- Provide mechanisms for support workers to meet and develop professional and peer support.

Lack of Support Staff. One of the biggest issues in the disability services sector is lack of support staff. This is two fold in that there is currently a crisis in available skilled and unskilled support staff, and more often parents or partners are unable to take on a caring role due to work and money constraints and so are reliant on paid support. In WA there are also suburbs and regional areas where this is worse than others. Unfortunately the economic boom is taking workers away from jobs in the health and social welfare sectors. It is unlikely this will change significantly without an influx of people willing to do this work or major changes to pay rates and career structures for workers in the sector. The impact of this is already apparent when there is discussion at federal and state levels of ten bed accommodation facilities and cluster housing which is more reminiscent of retirement villages as an answer to lack of staff and funding resources.

A flexible workforce? Service providers, family groups and people with disability have started engaging and employing support workers in different ways to try to overcome workforce issues as well as provide more flexible and individualised services. Examples are support workers as contractors with their own ABN's, agencies acting as payroll service only, and people paying cash in hand. Some of the issues which may impact future service systems are:

- Taxation rules on the definition of a contractor
- Workers not covered by workers compensation insurance
- Adequate and appropriate training not always occurring
- Real costs of support staff not identified

The diverse work of disability support workers. The work that support staff do is often seen as being homogeneous and paid at fairly standard rates while in reality there can be quite different roles required dependant on the person with disability. Some work is about prompting someone to do things for themselves, other work is personal bordering on medical care, some is purely domestic, some is about helping someone access the community. These can be with different ages and disability types yet there are standard training courses for disability support workers which may not take all these aspects into account. For example assisting someone to access the community may involve skills in helping them to build a relationship outside of paid workers. Whereas assisting someone else to get out of bed or prepare a meal may involve the skill of manual handling. Some people with disability do not want staff who have taken training courses as it stops them being flexible in responding to individual needs.

Implementation

Establish critical elements for the new scheme and begin with the eligibility and assessment processes. These could be developed using information from aspects of current systems.

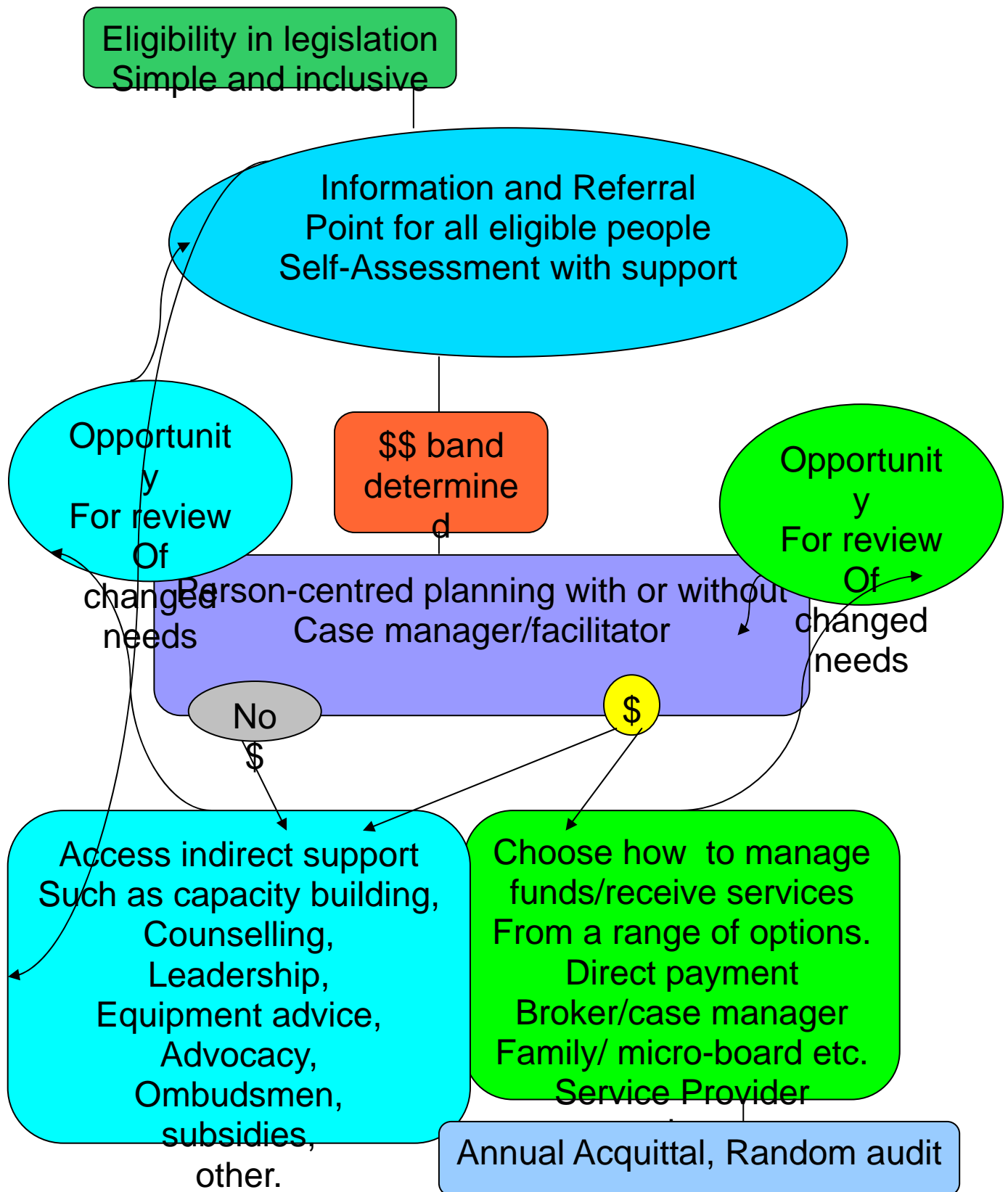
Currently there are some aspects that could be in a new scheme that have been implemented in various states and territories. For example, LAC in Western Australia and Queensland, direct payments in Victoria, New South Wales and Tasmania, Financial Intermediary in Victoria and Shared Management in Western Australia. Those that have had robust implementation and evaluation processes could be examined so as not to repeat those processes.

The new scheme could be trialled with new people coming into the system and refining by further development using robust methodology such as action research where people with disability and families can have input to identify and provide solutions to any issues.

Those currently already in the system would move over to the new scheme over a number of years. People already receiving funding / services would have a slow change starting with getting information on how much funding they have, and then what options are available. If they wish to change to some of the newer options such as a direct payment or those options we've mentioned earlier they can. There is an expectation where block funding currently exists changeover may take longer and require more work in the implementation of the new scheme.

Setting up of information points and new assessment processes such as the self assessment questionnaire and related funding bands etc. will be the most work.

Diagram of basic framework described.



References

Circles Network 2008 What is Person Centred Planning?

http://www.circlesnetwork.org.uk/what_is_person_centred_planning.htm

Cornell University 2008 Person Centred Planning Education Site

<http://www.ilr.cornell.edu/edi/pcp/index.html>

Crow, Liz 1996 *Including all of our lives: Renewing the social model of disability* Chapter 4 in *Exploring the Divide*, edited by Colin Barnes and Geoff Mercer, Leeds: The Disability Press, pp. 55 – 72

De Hoedt, B. 2002 *Community Living Indicators Project: Executive Summary*, Hootville Communications, Melbourne.

Electronic source: <http://afcl.org.au/resources/Pages/Publications.aspx>

Duffy, S. 2003 *Keys to Citizenship*, Paradigm Consultancy & Development Agency, Birkenhead.

Human Rights and Equal Opportunity Commission (HREOC) 2007 *Disability Rights, Towards Ratification HREOC workshop background paper*

http://www.hreoc.gov.au/disability_rights/convention.htm

Kendrick, Michael 2000 *When people Matter more than systems* Keynote Presentation for the Conference The Promise of Opportunity, Albany New York, March 27-28

Johnson, Roberta Ann 1983 *Mobilizing the Disabled in Social Movements of the Sixties and Seventies*, edited by Jo Freeman, Longman

Kennedy, J., Sanderson, H. and Wilson, H. 2002 *Friendship and community: practical strategies for making connections in communities*, North West Training and Development Team, Manchester.

Kenny, S. 1994 *Developing Communities for the Future: Community Development in Australia*, Nelson ITP, Melbourne.

Kinsella, Peter 2001 *Supported Living: The Changing Paradigm - from control to freedom*, Paradigm UK

Electronic source: <http://www.paradigm-uk.org> Paradigm UK

Pelka, Fred 1997 *The ABC Clio Companion to the Disability Rights Movement* ABC-Clio Publishers, USA.

Sanderson, Helen 2000 *Person Centred Planning: Key Features and Approaches*, paper commissioned by the Joseph Rowntree Foundation, UK.

Electronic source: <http://www.paradigm-uk.org/articlespcp.html> Paradigm UK

Williams, Robbi 2007 *Individualised Funding: A summary review of its nature and impact, and key elements for success*. Julia Farr Association, Adelaide Australia.

World Health Organisation 2002 *Towards a Common Language for Functioning, Disability and Health*, ICF, Geneva.