Submission Disability Care and Support

- PERSONAL RESPONSE

Improving the system:

A new system should be based around an assessment which is attached to an individual funding amount. This individual funding amount should be spent by clients and their families Decision making about amount of funding should be with Regional Assessment Committees attached to local planning areas.

Complaints procedures should have several levels. First level is complaining to Regional Assessment Centers about the amount of funding provided. If not satisfied with the outcome, clients should have the option of going to an independent committee with members consisting of carers, service providers and policy officers to look at situations from different angles and include all information in the decision making. If needed changes to service provision or policy should be a possible outcome of complaints made.

Decision making about types of services should be with clients and their families. Services should change their services types and the amount they deliver accordingly to the needs of clients. Funding bodies should either give the money to the services authorised by clients to deliver the care or to the client who can employ carers him/herself and be accountable through proving that hours care have been provided and paid for.

Activities that are now not included in disability care, but serve as therapy for people with disabilities should be tax deductible. For instance sport activities such as swimming, dancing, membership to sport clubs etc.

One of the risks of individualised funding is that a lot of time is needed for accountability of the hours provided services. This should be used flexible and the focus should be on outcome: behavioural improvement, including in society, becoming more independent, etc. Also family and friends should be able to provide for instance paid respite, so that family bonds become closer and part of the family gets to know the client better. Everyone will benefit from this in the long term, especially when there will be a support network available after parents pass away.

- PERSONAL RESPONSE

Who should be eligible?

People with mild, moderate or severe disabilities should be eligible. People with mild disabilities should be included, because the current system fails just as much for them as for people with moderate and severe disabilities. Even though when there is a mild disability, families and clients still only have access to services that are available and not what they need. A respite package cost easily $5000, while clients and families may prefer speech therapy, to which they have no access to.

Also victims of quickly degenerative diseases, such as MND or terminal cancer should be part of the disability scheme. Frail aged people should be included, just as it is described in the current Home and Community Care Guidelines, independent from age. A 90 year old can be healthy enough to do the housekeeping, while a 70 year old might be frail.

Health clients should receive their services in principle from Health. Only long term Mental Health clients should be eligible for receiving disability services. Motor vehicle or other injury insurance scheme clients should be excluded.

Children with just a development delay in one or two areas should not be included. Most of the time this is no longer an issue a few years later and these children should not use expensive disability services.

- PERSONAL RESPONSE

Who gets the power?

Funding bodies should in the end have the say about how government menoey should be spent. Assessors employed through Regional Assessment Committees undertake assessments and should decide on amount of funding for client, clients should decide on types of services they want to receive. Case managers can assist in analysing situations and actual needs clients have. Service providers can be consulted or they can make recommendations to Regional Assessment Committee after having experiences with clients.

- PERSONAL RESPONSE

What services are needed and how should they be delivered?

There are a lot of service types available for people with disabilities and the frail aged. Problem is that there is not enough service delivery in most areas and clients should be asked what services they want. At the moment clients can only choose services that are available and this might not be what they need, but they take it anyway, because what they need is not on offer. By starting with asking people what they actually need to get a better quality life, a whole different service system could emerge. An individual funding system will give a certain amount of money, which makes the client prioritise their needs and wants.

Another problem is that services are not organised well and are not flexible. Occupational Health and Safety is getting in the way of proper service delivery, even though policy does not describe that certain things cannot be done, such as lifting, taking clients shopping etc. Services should be flexible and meet clients' needs. Clients should not ne there to keep a service funded.

Same level of disability does not necessary mean same level of services. Some carers for instance experience a great level of stress, because of their own needs and experience with the disabled client, while other carers quite enjoy the caring role and for them it is not very stressful. This will only get clear through asking carers during the assessment. Also an assessment for anxiety and/or depression can be used.

- PERSONAL RESPONSE

Funding

A disability levy should be a mandated contribution paid by every Australian, just like the medicare levy. This money could be used to fund disability services and can dramatically improve amount and services provided.

Several timelines for deciding on funding should be existing, depending on the type of disability and urgency: from one month to 3 years. For instance with some disabilities that involve a quick degenerative disease with a short life expectancy should be assessed quickly with funding available within a month. Long term disabled people with the same care requirement expected for a very long time should receive funding within several months for about 3 years. When changes are expected a new assessment can be requested by client, carers or service providers.

It often takes a while before a new care system is in place and letting people apply every year is disturbing and unnecessary. Losing funding means losing a system that has taken many months to set up. This causes stress for everyone involved.

People who received a payout as a result of their disability should fund their own care until all the payout money has been used on care. This is currently difficult to implement and people receive free or heavily subsidised care while they use their payout for something else, such as buying a house with no money left for care.

Access to funding should not be means tested. Carers might decide not to work at all, because there would be no point doing this and easily get (more) health problems, because of the limited and depressing life as a carer. High profile Australians have the services for their children sometimes paid for by organisations, because they have the skills and money to access free services and can pay lawyers to fight for free services. This should come to an end with free services accessible for everyone.

- PERSONAL RESPONSE

Organising and implementing a new disability policy

A new scheme will take several years to develop. Policy makers should develop the policy and a plan for implementation. Pilot projects can be used to eliminate mistakes and make adjustment to policies. West Australia has experience with individualised funding and this experience should be used to eliminate as many mistakes as possible.

Organising the new system should happen within the funding organizations, such as the NSW Department of Human Services, Ageing Disability and Home Care (ADHC). Quality control should exist through quality reviews by funding bodies, such as ADHC's Integrated Monitoring Framework. As a part of this services give their quarterly financial details and output and outcome. During an on-site review services provide evidence of running a high quality organisation through minutes of meetings, clients and staff surveys/ interviews etc. This should happen every three years.

An end should come to the thousands of small organisations providing just one or a few service types with massive overhead cost. Services could be joined into Multi Functional Organisations offering a variety of services and choice for clients.

- PERSONAL RESPONSE

You may have many other ideas for a good scheme

A good scheme will provide the right balance between a 'one door' approach with the same measurements and outcomes for the same type of clients and a flexible approach, which caters for emergencies and changes in someone's life. Clients should have choice from different services provided by different organisations.

In the Netherlands they have implemented the 'one door' approach, where everyone has to go through the same assessment procedure. This has increased fairness, because all assessments are done the same. It also has increased bureaucratic procedures which is a negative by-product. The waiting lists are still there, because only more money will solve this problem.

If possible, I would like to receive updates on the enquiry.

Yours sincerely,

Name Withheld