

Response to the Productivity Commission Inquiry into a Long-term Disability Care and Support Scheme

A Submission by Housing Resource & Support Service Inc

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**HR&SS Response to the Productivity Inquiry into Long-Term
Disability Care and Support Scheme.**

**Summary
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1. Though there have been some advances for people with disabilities (pwd) over the past 25 years there is still much discrimination and disadvantage experienced by pwd.
2. People with disabilities have a great diversity of needs and are often excluded due to their low economic circumstances. (Q 2)
3. Increased access to housing,(public, social and private), and the separation of housing from support are essential in any long term disability care and support scheme. (Q 3)
4. HR&SS endorses the National Disability Insurance Scheme.
5. Total access to generic services by pwd will assist in greater equality for people pwd. (Q 4)
6. Government must fairly fund case management/advocacy for pwd.
7. Government must continue to promote self-determination for pwd through innovative and diverse funding opportunities and programs, such as direct funding. (Q 4)
8. The disability service system is ridiculously complex and fragmented. Development of a clear and transparent disability service system, and its relationship to other welfare, education, employment or support services is an absolute necessity. This must include a transparent appeals /review mechanism. (Q 1)
9. People with disabilities and their families/key support people need to be at all times considered the centre of any systems/programs development. (Q 2)
10. Minimum funding levels must be established as national guidelines that provide for housing, modifications, homelessness and tenancy support for pwd. (Q 3)
11. Flexibility across funded programs is essential. (Q 3)
12. National and state legislation for private tenancy which enables modifications to properties without disadvantaging pwd. (Q 2)

13. National guidelines and targets for service providers which identify individualized and direct funded services for pwd must be established. As well as establishing housing separated from support services, a range of innovative and flexible housing models and tenancy support services for pwd.(Q3)
14. People with Disabilities who have are from diverse cultural or linguistic backgrounds, or who are Aboriginal or women with disabilities should be included in national targets and guidelines, ensuring their particular and complex needs are met. (Q4)
15. Increase public and social housing to increase the stock numbers and therefore access to affordable and appropriate housing for pwd. (Q5)
16. Government needs to acknowledge that pwd have much to offer and are a valuable asset to the Australian community. (Q6)
17. Include pwd in all consultations and reference groups as well as service providers. (Q7)
18. Increase direct funding to consumers to avoid duplication. (Q8)

Response to the Productivity Commission Inquiry into a Long-term Disability Care and Support Scheme

Background

Established in 1986, Housing Resource and Support Service (HR&SS) is a consumer-controlled service with the Governance Board made up entirely of people with disabilities. HR&SS is an incorporated, not-for-profit organization whose work focus lies with the provision of support and services coordination, housing, case management and planning.

The HR&SS philosophy has always been one of consumer empowerment and self-determination, offering people choice in their support services and assisting them to live as they choose in the community. HR&SS's vision is that people with disabilities living in Victoria have access to the fundamentals necessary for quality living. We assist more than 250 consumers each year, and these are mostly clients with long-term disabilities from birth or acquired early in their life – these are not simply ageing-related disabilities.

There are many areas of on-going difficulty for people with disabilities (pwd) who make use of our service or for whom we are one port of call in their search for suitably designed housing and appropriate support services.

HR&SS has been in existence as a support service since 1986, and though there have been advances for people with disabilities over this time, in some areas there is little change; they still experience discrimination and disadvantage in many areas that prevent full participation in employment, education, family life, and in the community in general.

People with disabilities have a great diversity of needs, as do other groups, but are usually assessed as being from the lowest income group in society¹ and are thus excluded from full participation in society not only due to their disability but also because of their economic circumstances.

Access to housing and appropriate support services is essential to enable these citizens the full participation and acceptance in community life promised by the Charter of Human Rights, the Disability Discrimination Act, and the Disability Services Act.

We endorse the concept of a National Disability Insurance Scheme as a way of improving the planning and delivery of services to people with disabilities.

1. How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?

We acknowledge that people with disabilities have special needs and believe they should have the opportunity and support to identify their own vision for life in mainstream society. The ability to access generic services is important but this requires a greater clarity and security of support services. This must be provided through government departments or other social service providers to ensure pwd are empowered and given clear access always.

“Power” in this context means having access to and the possibility of negotiating with the person making the decisions about the supports that you require to live independently in the community; this is seldom the case. For example, many of our clients apply for support funding under the Victorian Individualised Support Plan program. The case-planning role of this program is a short-term function that is usually contracted out by the Department of Human Services and therefore the practitioner does not have an ongoing relationship with the consumer. Improvements to the administration of such

¹ Beer, A & Faulkner, D; *The Housing Careers of People with a Disability and Carers of People with a Disability*; AHURI, 2009.

programs should include some avenue for people to talk directly to the staff in DHS who can actually make decisions about their application.

We believe that the current funding of Individualised Support Plans in Victoria is not fully a rights based approach – it still has elements of paternalism and the welfare handout philosophy of recipients expected to be grateful for what they get (including parents of children with disability) and not complaining.

Self-determination

Consumer self-determination should be supported through a range of service responses including individual funding, direct funding and realistic funding levels. Direct funding can help pwd to control their support requirements while living in the community, thus reducing the need for residential care facilities.

Without adequate resources pwd remain disabled by society.

Bureaucracy

From our work with consumers, most find engaging with the DHS bureaucracy a daunting experience. People with disabilities understand there are limitations to funding levels and eligibility for services, and are willing to work within the limits, but often they can't get to speak to anyone about it.

One problem is the lack of information that consumers can easily relate to. There is not a lot of information available about Individual Support Planning but what is available for consumers is too general. People with disabilities often want someone to talk to, as for many this is their preferred mode of communication. This could cross all areas of life for pwd – housing, health, education, recreation, etc.

With regard to Individualised Support Planning, DHS tends to work through intermediaries rather than talking directly to the person with the disability, and therefore – to consumers – it seems that DHS is avoiding contact with people with disabilities, who feel avoided and excluded. Because clients are not talked to directly, they don't get a chance to state their wishes directly.

Another major issue is the fragmentation of the service system. Again, this is true for all those in need of social assistance, not just pwd.

For some clients it seems that DHS is so far removed from the consumer that clients may not be aware of their role. It is very difficult for clients to know about the appeals process, as knowledge about this does not seem to be encouraged – it is hard for consumers to find out how to make an appeal.

Given their sense of disempowerment, it is also difficult for pwd to feel they have the right to appeal.

With regard to decision making about the Victorian Disability Support Register, there should be more transparency, including guidelines as to how and where consumers can appeal.

Case example: One of our consumers received a letter from DHS about their DSR application but could not understand it, so wrote to DHS about it but did not receive a reply – instead, DHS contacted the HRSS planner about the consumer. When senior staff at HR&SS reviewed the original DHS letter they also found it incomprehensible.

The intervention methods of DHS staff with regard to consumers receiving Case Management or related services also needs clarification. One of HR&SS's consumers has reported that DHS staff were very confrontive, entered her home in an arrogant manner and made judgemental comments about the consumer's family life and parenting skills, then demanded that she sign documents. By this stage the consumer was so intimidated that she complied. In cases such as this it would be more diplomatic to work through the Case Manager to address concerns in a less threatening manner.

There also needs to be better and quicker coordination with support persons working with consumers. In some instances it can take several months for a plan to be approved through DHS, but when a new ISP is arranged DHS does not send a copy to the Case Manager, so the support agency is not aware of progress until they are contacted by the consumer.

Appeals

There must be an independent complaints and appeals process regarding support assessments, reviews, and access to support services. Members of the appeals tribunal must not be directly associated with the government service that was responsible for making the original decision.

2. How should the amount of financial support and service entitlements of people be decided (and by whom)?

The level of support being offered to people with disabilities to live in the community is not adequate for a truly independent life with dignity. The government package of assistance, usually for the provision of personal care services in the home, is at the minimum level, and often not flexible enough for the variety of support services required by the consumer.

DHS is following the trends being implemented in Britain, where de-institutionalisation is being achieved through funding allocations to individual consumers to manage their own care in the community, with appropriate guidance. These consumers effectively become their own case managers and decide how to use the funds for which they are eligible; they purchase the services they want.

The Australian implementation of this approach is significantly different in that a much lower level of funding is allocated per consumer and there are considerable restrictions on allowable expenditure. In Victoria under the current funding for personal support services, consumers are generally offered up to 34 hours per week as the maximum for personal care services, and then must argue their case for extending this level.

Case example: A 70 year old consumer with severe multiple sclerosis who is totally dependent, to the extent that he can't get out of bed and can't activate his MEPACS unit on his own, receives 34 hours per week of care, which is considered adequate to meet his needs, and he must justify a claim for any further allocation.

We believe that public service gate keepers are controlling access to the financial resources allocated for disability support, and this places them in a conflict of interest with regard to meeting consumer's needs while maintaining departmental budgets. We also believe cost savings could be made if the administration of disability support was streamlined and standardised under the control of a single system.

Minimum funding levels should be established as national guidelines that provide for:

- Access to appropriate housing, modifications, and tenancy support, as in the National Homeless Sector programs.
- Adequate income for living with dignity and participating in community life.
- Flexible guidelines to allow for individual circumstances or crises.

3. What kinds of services particularly need to be increased or created?

In Victoria, the operations of the Disability Support Register (DSR) must be better resourced and more transparently administered. At present, the DSR is not widely known by pwd. To apply one has to know where to get a booklet, have to understand how to answer the questions, and also know the “secret code” of being emotive in your presentation. Not everyone is sufficiently technologically advanced to be able to produce a DVD proving the extent of their disabilities, and yet this is the type of presentation that will, reportedly, receive a quickly sympathetic response.

Some clients have to argue their case regarding the level of care required on medical grounds to a review panel that does not have medical expertise. There is no dignity in having to “prove” the need for ongoing bowel care when you already have a medically diagnosed deteriorating bowel condition.

Flexibility across funded programs is essential. For example, combining the Case Planning and Case Management roles (of the Victorian ISP program) into one position would be useful for some consumers, as this would reduce one level of complexity in negotiating changes to support plans. The current variety of personnel and review mechanisms makes it unclear who to go to for reviews and appeals – this is confusing for service providers and consumers

National legislation on universal housing design that facilitates modifications would mean that people with disabilities might be able to access affordable, appropriate housing and secure tenure. At present this is problematic because pwd form one of the lowest income groups in Australia and are therefore disadvantaged in competing for private rental and home purchase. This is becoming even more of a problem because of greater competition with the able-bodied, working population for secure housing.

Unfortunately, the extra cost of modified housing for the disabled also effects the federally funded community housing sector; the consequence is that people with physical disability (or groups supporting them) are being asked to raise the extra capital to incorporate accessible design – in effect, there is an extra burden being placed on pwd to access “normal” community housing. For

example, some community partnership models can build modified accommodation for the specific needs of people with physical disability, provide the groups are able to contribute up to \$250,000 towards the cost of building units. Such costs are prohibitive for most individuals and groups.

In another example, a community-housing provider is developing units targeting a mixed social grouping of people with different income streams. As a partner to this development, HR&SS is being asked to donate \$100,000 in order to have several units modified to the needs of pwd.

These arrangements illustrate that there are extra burdens being imposed, directly or indirectly, on a particularly vulnerable section of the community.

Case example: several HR&SS consumers accepted into modified properties with social housing organisations have been asked to contribute financially to the cost of modifications, which has included kitchen renovations, building access ramps, and modifying entrances, etc. It then requires significant effort by consumers and HR&SS workers to challenge and appeal such demands. In the meantime the consumer is under the constant stress of having to find alternate accommodation in order to “free up” the premises.

4. How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

The sector needs more resources and better transparency about funding guidelines and allocation processes. Bureaucratic decision making is often a drawn out process that creates confusion and annoyance – it can take up to 2 or 3 years for a consumer to be accepted onto the Disability Support Register, but occasionally this can be even longer. DHS does not appear to maintain a waiting list per se, and at times consumers are told they have to wait until a particular pool of funding becomes available. It is not unusual for clients to be told that they have been registered on the DSR but there is no money available to fund their requirements. Because of lack of transparency, consumers believe there is a secret priority list.

The onus seems to be on the consumer to fix the systems – people who have little idea how the system functions have to write letters of complaint to get the system changed. As an agency supporting consumers, we grapple with the complications of a complex service delivery system – even with our 25 years’ experience in the industry it is still difficult for us to understand the intricacies and changes that occur. How can we expect clients to understand?

Contracting out service delivery to the private and not-for-profit sectors should also take into account consumers’ needs as well as funding efficiencies. We

believe that people with disabilities who cannot “attract” higher subsidies can become marginalised consumers; for example, a large service organisation declining to support a consumer because the level of funding does cover the organisation’s travel costs for home visits. In another type of example, Case Management services may be funded at \$56 per hour through one government program and only \$46 per hour through another. This is a form of hidden discrimination that can occur because of economic competition.

As well as targeting support for women with disabilities, HR&SS also promotes the needs of our Koorie community and people from cultural and linguistically diverse backgrounds. These are groups for which there can be further layers of structural and hidden discrimination as well as their disability. For example, we have found that people of CALD background can be isolated in an area without ethno-specific services and without any of the mainstream agencies having appropriate bilingual staff – no one wants to work with these individuals because it’s too hard, too expensive, or they live too far away.

We believe that the government has the responsibility to acknowledge that disability and other social/cultural factors are part of the normal diversity of Australian society, and need to be responded to with fairness and equity. Any national framework should include incentives and guidelines for all funded services organizations to incorporate the individuality of cultural responses as part of their service philosophy, and be required to develop the expertise to work within a multicultural environment. At a minimum this should require them to use interpreter services or co-workers rather than deny support.

We believe there could be cost savings if the administration of support services for people with disabilities was streamlined at the national level, especially so that there would be consistency across states and regions. A rights-based approach to consumer empowerment is more possible if there is consistency in the eligibility criteria for access to services, clarity in programs, and flexibility in administration to ensure individual needs are met.

5. Are there ways of intervening early to get improved outcomes over people’s lifetimes? How would this be done?

We believe that an integrated approach is necessary in order to achieve and maintain outcomes over a lifetime. A key aspect is access to appropriate housing, because without access to secure accommodation it is very difficult to establish local support networks and participate in community life.

We believe that the level of support being offered to pwd to live in the community is not adequate for a truly independent life with dignity.

The government package of assistance, usually for the provision of personal care services in the home, is at the minimum level, often not flexible enough for the variety of support services required by the consumer. DHS is following the trend from Britain, where de-institutionalisation is being achieved by funding individual consumers to manage their own care in the community. The Australian implementation of this approach is significantly different in that a much lower level of funding is allocated per consumer, there are considerable restrictions on allowable expenditure, and there are several layers of government control over funding for individual consumers.

We firmly believe that current government policy focussing on employment as a social change mechanism is inappropriate for people with disabilities if that is seen as the sole means of income distribution. Employment is a goal that many pwd aspire to, as do most people, yet there are many instances where this is unrealistic, sometimes because of genuine incapacity for some people, other times because of discriminatory employment practices, and the often practical reality that paid employment of only a few hours per week does not create financial independence. Government consistently denies what added value pwd give to the community simply because of their difference, and this valuable contribution to society can include “unpaid employment”, that is, the voluntary work that many pwd contribute to society.

Once again, suitable housing is one of the best forms of support for people with disabilities. There are nearly half a million people in Victoria with some form of disability, and three-quarters of these have a physical disability; many of these will need modified housing in order to living independently. In Victoria only 6% of disability service consumers live in institutional accommodation, 32% in group homes, and nearly two-thirds (63%) in other accommodation types. It is clear that the state and community housing sectors will be under the greatest pressure to respond to the growing demand for appropriate housing:

“... current policy frameworks view public rental housing as the most appropriate mechanism for directly assisting persons affected by disability with their housing need. This has contributed to a concentration of persons with a disability in the public housing stock, with 40 per cent of new entrants being disabled. However ... much of this stock is seen to be physically inappropriate for persons with a disability because of the design of the dwelling, distance from public transport, poor quality maintenance etc. It is also appropriate to question whether the systems of public housing management are appropriately focused on the needs of persons with a disability, given the current and growing demand from this group.”²

² Beer, A & Faulkner, D; *The Housing Careers of People with a Disability and Carers of People with a Disability*; AHURI, 2009. p50

6. How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

By government and the community redefining what “work” is.

By welcoming pwd diversity rather than making them be “average”.

Encouragement for participation and engagement in community and work can be more flexibly interpreted. People with physical disability often cannot attend community activities without access to transport, and membership fees for health and recreational activities, for example, can be prohibitive for people on low incomes, yet our consumers are often expected to fund such activities from their “normal” income source.

Participation in activities is important to maintain health as well as community engagement, but people with disabilities often can’t afford such “luxuries” because they are trying to survive on a disability pension.

We need a positive funding support model that is driven by individual circumstances and focussed on resourcing people for social inclusion. For example, the HR&SS Board is comprised entirely of people with disabilities, and they are responsible for the governance of the organisation. To assist with such participation, HR&SS provides Board members with training in governance and management skills, issues taxi vouchers to attend meetings, and also hires care workers for appropriate meetings to provide for personal care needs. This is not funded by government yet is “educational” and “work” in its nature.

How people with disability can participate in and contribute to society, work and family is dependent on the social and physical infrastructure that is created to facilitate participation. For example, Barcelona is a very accessible city with a visible presence of people with disabilities in community life as consumers and workers in retail services and the tourism industry. This is greatly assisted by the city’s transport system that caters for people with physical disabilities.

In contrast, most of Melbourne’s trams are still not accessible for people in wheelchairs, so often their only feasible means of transport is using the expensive option of taxis.

Participating in community activities is therefore problematic where disposable income is an issue, which would be the case for many people reliant on pensions or disability benefits.

Individualised Support Planning could be strengthened by making it flexible enough to allow funding for social inclusion and participation as a priority. As mentioned recently by one disability support group:

“social inclusion is more than physical presence – it’s also a sense or feeling that you belong, are welcomed, connected, have something to offer or reciprocate and are surrounded by a range of relationships other than those which are paid or based on diagnosis. ... [W]e can’t force relationships to happen but we can build a context for relationship to grow and flourish with other community members. Thus enabling and supporting people with a disability to also experience, contribute, learn, problem solve and belong to what is good and difficult about community.”³

7. How can a new system ensure that any good aspects of current approaches are preserved?

Firstly, ensuring pwd are included in all decision making processes for these changes.

We suggest that a variety of consultations (such as this one) be held with consumers and disability advocacy groups before any national scheme is implemented in order to obtain appropriate feedback.

A reference group drawing on expertise from government departments and state peak bodies and advocacy groups representing people with disabilities is essential.

8. How could a new system get rid of wasteful paper burdens, overlapping assessments (the ‘run around’) and duplication in the system?

A more sympathetic and less bureaucratic administration would be helpful.

At times, people with disability are treated very paternalistically by government services, even when there is no logical reason for doing so. When a person receives unemployment benefits, sickness benefits or the aged pension, the government does not interfere in any decision to buy medical accessories necessary for personal health and wellbeing. Why is it necessary to obtain

³ Deb Rouget “Some Reflections on What Might be Needed to Assist People with Disabilities to Become Authentically Included in the Community” in Bigby & Fyffe (eds) *More than Community Presence: Social Inclusion for People with Intellectual Disability. Proceedings of the Fourth Annual Roundtable On Intellectual Disability Policy*. Bundoora: La Trobe University, 2010

permission from some bureaucrat if the funding is received through personal care funding?

Case example: A client who has a long term physical disability and receives funding for personal care must ask permission to use some of that funding to buy surgical support stockings for an ongoing medical condition. Therefore a necessary cost of a few hundred dollars has to be referred for a decision by the bureaucracy, which means that the cost of the bureaucracy will probably be greater than the cost of the item.

Case example: When case plan needs to be changed, it has to be referred to an appropriate authority for it to be reviewed. In one instance it was argued that the case plan had already been set for the next 3 years and therefore could not be reviewed before then. This is example of some of the absurdities in the current system that are disempowering and demeaning to clients.

One method of reducing the runaround with some Individual Support Packages could be to combine Case Planning and Case Management roles where there is a long-term support relationship with the consumer. This could overcome the problem of consumers having to be constantly seeking permission to change their plan.

Case example: A consumer has been allocated one hour per week of case management support for six months. She believes this is inadequate and should be increased to three hours per week. Her circumstances have changed greatly over the last 18 months because of multiple disabilities, including sight impairment, mobility and other disabilities, which means she:

"[N]o longer fits the box, and the support organisations as a whole don't know where to put me in the services. HR&SS has been doing its best, but the review done last year doesn't quite fit any more. ISP is not as flexible as I was told. ... When I signed up with ISP there was a slight understanding that it would be ongoing, but then I was told it would be reviewed after one year.

"I feel I'm between a rock and a hard place, because my eyesight is now more of a problem and there is no guarantee that my sight will improve. ISP is not quick enough in responding to individual changes. HR&SS and clients are trying to do the best they can but the Department says they don't do it that way anymore and each region has slightly different views."

We trust you will consider sincerely our response, as the proposed changes will have monumental and positive impacts upon all Victorians.

We look forward to a prompt response and implementation of the many needed changes from this important consultation.

Yours sincerely,

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