

A secular community benefit organisation, PHCS and Regional Home Care Services (RHCS) specialise in delivering person centred solutions to support people to live at home with dignity-in the disability, aged care and mental health sectors.

With annual turnover of \$36 million, 850 staff and supporting 2,000 people per fortnight across a variety of disability, mental health, ageing and community programs, PHCS is a recognised leader in innovative approaches to consumer directed care and individualised service design and delivery.

PHCS is based in Perth, with offices in Osborne Park and Jandakot. Regional Home Care Services has offices in Toodyay and Geraldton, providing support to people in regional areas. PHCS/RHCS is not affiliated with any national provider group.

PHCS, which has served Western Australia for 40 years, is supported by a robust Board, and a strong, stable management team and staff.

PHCS offers this submission from the perspective of its support to people across three sectors. Our comments reflect our experience in working with the people being supported and within the systems that provide funding. This submission seeks to:

- Provide our views about the values and principles necessary in making changes to Disability Care and Support in Australia,
- Address some of the specific questions posed in the issues paper
- Express our view of the fundamental place of mental health within the context of disability care and support reform
- Discuss specifically our experience related to the consumer directed support spectrum and why this model is critical to disability care and support reform.

We cannot answer all of the questions posed by the Issues Paper, but we can identify key values and principles of a reformed system, identify mechanisms that are working currently and provide insight as to how the system could be changed.

**Values and Principles:** The provision of Disability Care and Support should be underpinned by values and principles. At the core of this support is the principle that the person being supported has the right to be in control of their life. This means that people have a right to:

- Make choices and decisions for themselves;
- Grow and develop in their relationships;
- Be present and participate in the community;
- Have valued roles and contribute; and
- Develop their talents, interests and abilities

These rights are consistent with the United Nations Convention on the Rights of Persons with Disabilities. National reform of Disability Care and Support needs to promote and create actions consistent with this convention. Other values and principles of Disability Care and Support include:

- 🗺️ **Person Centred Support:** Support should be built with the *person with disability at the centre* of support planning. People themselves are the experts in their own lives. Thinking of the person with disability as the centre of a 'bullseye', circles of support should be designed with the person in the centre in control. It is important, therefore, for any system

built to begin from the perspective that the person with disability is in the centre of that support and in control of their own plan. Often, the person with disability has a primary carer. Their needs and dreams should also be considered and the person with disability and their carer (often a family member) should not be artificially separated.

- ✚ Flexibility and Creativity of Support Options: Because every individual is unique, and one plan does not fit every person, Disability Care and Support should be reformed to support **flexibility around different solutions** that could be created. There should be an incentive for **creativity and sustainability** without disadvantaging people by decreasing their funding allocation substantially. Support should be responsive to the changing circumstances of the individual whether these are improvements or an increased level of support need. Support should be as individual and flexible as the person themselves. This requires agility on the part of a larger framework and at the organisational level.
- ✚ Equity: Disability Care and Support should be equitable, providing each according to their own needs, choice and preferences. No one should be worse off or unfairly worse off than in the current system.
- ✚ Community Inclusion: No person is an island and the contribution and citizenship of people with a disability should be recognised in their community. The reality is that disability is a community issue, affecting the whole community; therefore, the whole community should contribute to the solution.

### Things to Keep

Western Australia is fortunate in many ways to be on the forefront of support to people with a disability, with a functional Disability Services Commission and local support through Local Area Coordination (LAC). The importance of supporting people with disability in Western Australia is bipartisan, sitting firmly in the agenda of government, whatever their political philosophy. We see that there are parts of the existing system which should be retained when considering reform. These include:

- ✚ Individualised service at a local level, such as LAC.
- ✚ Using existing mechanisms
- ✚ Retaining existing services and structures which meet the values and principles of a reformed system of the provision of Disability Care and Support.
- ✚ Supporting broader social interventions ongoing such as access improvement and universal design.

### Things to Change

We strongly support a need for a change in Disability Care and Support and have identified a number of areas in which we believe change should occur under reform.

- ✚ Mental health should be 'in': Mental health should be in the scope of the Disability Care and Support reform. People with mental illness have a disability as such and this disability should be recognised along with physical or intellectual disability. Like people who are challenged by other disabilities, people with mental illness can contribute and have right of citizenship. Putting mental health into the Disability Care and Support discussion will potentially allow funding to be allocated to assist people with mental illness on their recovery journey and can promote inclusion into communities and decrease of stigma.

- ✚ Disability Care and Support should be viewed from a strengths based perspective rather than a deficit based perspective: People with disability are employees, consumers and contributing members to society. Their disability is a part of who they are, but not a definition of their capacity and heart. Reform of systems should begin from the perspective that people with disability have something to offer the community of real value- that there is reciprocity in our relationships and not a sense of people with disability only receiving benefit, but putting into relationships and community.
- ✚ The perception that people with disabilities can't and don't work needs to change: People with disabilities can and do work. They are valuable contributing members of the community. People with disabilities should be afforded the opportunity to participate in work and have an incentive for doing so. Their quantum of support and funding should not be unfairly disadvantaged by taking up paid employment.
- ✚ Contribution does not equal productivity: People with disability can make a contribution and be productive, regardless of whether or not they are in paid employment. People's contribution to the community in which they belong is productive, and enhances the community itself. Everyone can learn, everyone can communicate, even without words and the community can benefit.
- ✚ Disability is not the property of the person: Disability is not the property or issue for a single individual. It has a societal aspect. Not only is the person with disability affected by their circumstance, but their fathers, mothers, siblings, co-workers and larger community is impacted. Both people with disability and people who love and care for them affect their community by what they can and can't access, by what they choose to purchase, by events they choose to attend, by schools they attend and by services they support. Disability is not an individual issue, but one for the whole community.
- ✚ Provision of Disability Care and Support should be equitable: The allocation of support for people should be equitable across similar needs/circumstances.
- ✚ Systemic shuffling should be eliminated: There is a clear relationship between people with disability and other significant areas namely Health, Mental Health and Ageing. These areas should not continue to operate in silos, decreasing productivity across the system and increasing the confusion for people with disability. People with disability also age, and people who age have acquired disability. People who age and/or have disability can have mental health issues either related, or not, to their individual circumstance. People should be able to access support across any of these areas with a minimum of confusion and anxiety. Passing the buck between ageing, disability, mental health and health is not going to assist the government in achieving its overarching policy goal to enhance the quality of life and increase the economic and social participation of people with disability and their families, including enhancing and protecting their rights.

### **Responses to Specific Questions: Disability Care and Support- Productivity Commission Issues Paper**

As a result of consultation and PHCS' involvement with WAIS (WA Individual Support), we can offer responses to some of the specific questions posed in the issues paper.

## Who should be eligible?

*Q5. Is need the appropriate basis for eligibility?*

A5. Yes. The disability community has been driving an *Unmet Needs* campaign across Australia for more than a decade. The concept of unmet needs resonates strongly within the disability community, the disability services sector, amongst politicians and bureaucrats, and across the wider community. Importantly, *Unmet Needs* incorporate widely embraced concepts of a fair go, equity and looking after society's most vulnerable.

*Q6. What groups have the highest needs or have been most disadvantaged by current arrangements?*

A6. It is difficult, and perhaps not constructive, to pit one disability group against another in the search for the 'most disadvantaged' or 'most needy'. There are many ageing parents who have cared for sons and daughters with intellectual or developmental disabilities for most of their lives with little respite or formal support. There are many young and middle-aged adults with intellectual or developmental disabilities who are marooned in the parental home and unable to move into their own home due to the lack of needed supports. There are also many people who have developed a neuro-degenerative disease in later life and who fall between health, disability and aged care services.

While needs should be the primary factor in determining eligibility, assessing need may not be straightforward. The appraisal of how an individual's functional limitations (mobility, self-care, communication) affect their need for support and care depends on the precise assessment tool and the way in which it is used. As an illustration, the ABS estimates of the numbers of people with disabilities of varying severity are based on self-assessment using the criteria in Box 1 of the Discussion Paper.

FaHCSIA's criteria for providing carer allowances for care of children with disabilities depend on several overlapping classification approaches. Children are assessed against the 'Lists of Recognised Disabilities', which contain certain disabilities and medical conditions that are consistently severe enough to qualify the carer for the allowance (for example, Down syndrome). Where a child's medical condition or disability is not on the Lists, they are assessed using the Child Disability Assessment Tool (CDAT). The CDAT measures the child's functional ability according to standards appropriate to their age and is based on information provided by a treating health professional and the carer. CDAT does not assess the care needs of the child, which is independently tested as one of the criteria for eligibility for the allowance.

Some think that severe or profound disability should be the basis for eligibility. However, this classification may not always be appropriate for deciding who should get the most assistance. For example, the ABS approach to measuring severe or profound disability may exclude people with mild intellectual disability who do not face the specified core limitations, but whose actual capacity to participate in society may be lower than those identified as having a daily core activity limitation. Early service provision and periodic mentoring may allow their full participation.

Similarly, in some cases, it may not be appropriate for a person classified by a given definition as having a severe disability to be eligible for the scheme (e.g. when the disability is expected to last for a relatively short period).

*Q9. To what extent should other facets of a person's life: their location, access to services, family circumstances and any disadvantages affect eligibility?*

A9. All of the examples are relevant in the overall consideration of eligibility.

*Q12. How do you ensure that eligibility processes are consistent, fair and transparent?*

A12. Ensure that people who are engaged to assess eligibility are well qualified, well supported and well resourced to undertake a careful and thorough analysis of the applicant's needs, circumstances and preferences – and those of their caregivers.

*Q15. What are the implications of adopting more or less generous eligibility criteria on fairness, adequacy of services, costs and incentives, and how could these be addressed?*

A15. Using person centred and individualised approaches to service provision, ensures that people get what is adequate for their needs. Assessment of allocation of resources/support needs should be person centred, thus ensuring that adequate support for each individual is determined.

A narrow coverage would ensure that those who are most needy receive an adequate allocation of resources. Any less than an adequate allocation may prove of little extra value than no allocation at all (e.g. it is hard to 'half live' in the community or be substantially under-supported when living independently of family).

The new scheme should sit alongside existing state and territory support systems as many service users are happy with their current support arrangements, may face unnecessary dislocation and uncertainty due to new funding levels, administrative arrangements, support options and service providers.

*Q16. Should the scheme apply to new cases of disability or to all people with existing disabilities?*

A16. Ideally, the scheme should apply to both existing and future disabilities. There may be a middle alternative that includes people with newly acquired disability and people whose needs are not adequately met by current services.

### **Who makes the decisions?**

*Q21. How can people with disability and their carers have more decision-making power in a national disability scheme? How would the success or failure of new approaches be tested?*

A21. Direct control of funding is a major attitudinal shift. The extent to which people with disabilities and their family members control the funds they received will be directly correlated with the extent of decision-making power they have in the scheme.

However, it is important to acknowledge that most people and families who have had no previous experience of controlling their own funds will require information, support and guidance to effectively use their funds to broaden the support horizons from formal and traditional services to informal and community-based supports.

Using person centred approaches will ensure decision-making power is retained by the individuals and their families. This process, in conjunction with individualised funding, will enable families to design the service that best meets their needs. To be properly involved in decision-making processes means that families and individuals need to be consulted and given opportunities to influence and develop policies, programs and services.

*Q22. What should be the decision-making powers of governments and service providers?*

A22. Government decision-making power should be limited primarily to determining eligibility, establishing the annual funding level and reviewing ongoing eligibility.

Service provider decision-making power should be limited to deciding whether or not to provide services in the first instance, what services it is willing to provide and how it is willing to provide those services, what to charge for those services and if or when to withdraw any or all of their services.

*Q23. What have been the experiences overseas and in Australia with individualised funding, including their impacts on outcomes and costs? What lessons do these experiences provide for adopting this approach as an element in a national disability scheme?*

A23. Individualised funding has been progressively implemented across Western Australia since 1988 and applies to all recipients of State government disability funding since 2005. There have been regular internal evaluations, external evaluations and doctoral research into the operationalisation, cost and impacts of these services over that whole period. These evaluations are available from the Disability Services Commission in WA or the corresponding respondent. No other state or territory has such a comprehensive and well-tested system of individualised funding in place.

*Q24. Should individualised funding include the capacity to save some of the annual payment for future purchases of services or borrow from future payments to pay for current services?*

A24. Yes. Having some capacity to accumulate funds, or even draw down future funds, allows people to plan better for the future. This may include purchasing an accessible vehicle, arranging home modifications or procuring expensive items of equipment. It may also include saving up for an occasional holiday. However, safeguards may need to be put into place, especially in regard to drawing down future funds. For example, any such draw downs could be limited to 10% of the annual funding allocation and also limited to five years of accumulation. Under this scenario, the maximum drawdown from future funding would be limited to 50% of the annual funding allocation.

*Q25. How should the national disability scheme support people's decision-making under individualised funding, taking account of the spectrum of disability — both in terms of the nature and severity of disability? Should all people be able to access individualised funding, and if not, what guidelines would be appropriate?*

A25. All people, regardless of the nature or severity of their disability, should be able to access the scheme. Where the person is unable to make their own decisions, court-appointed family members or guardians should be appointed to assist them with the decision-making. There is good evidence, accumulated from local practice in WA particularly, that individualised funding is well suited to people with significant disabilities. This is contrary to view of a number of service providers who do not operate individualised services.

For all people to utilise individualised funding, there needs to be a range of options available (e.g. self managing, financial intermediary, case manager/broker) to assist with fully exploring options and managing the funds.

*Q26. What are the risks of individualised funding and how can they be managed? What guidelines would be appropriate? How would any accountability measures be designed so as not to be burdensome for those using and overseeing the funding?*

A26. Evidence collected in Western Australia suggests that there is less risk associated with individualised funding arrangements than with traditional block grant payments paid to service

providers. This is because the person with disability, or their family, is aware of their funding level and able to comparatively assess the quality and intensity of supports they can receive with their funding allocation from various providers. In effect, disability services become demand driven and providers become subject to market forces. Consequently, effective and efficient services are more likely to flourish and grow - while poorer services are likely to wither and die.

However, support for individuals to budget and plan their services is sometimes necessary, as there have been instances of people over spending on their support allocations and, consequently, either having insufficient funds for the duration of the funding period or moving into debt.

It is acknowledged that providers can be at risk in circumstances where several clients simultaneously exit for various personal reasons, such as relocation, death or long term hospitalisation. This is a greater risk to small to medium sized organisations, and can impact on the sustainability of the program and the ongoing employment of staff. It can also impact on the organisation's ability to offer permanent employment to staff.

On the question of guidelines, the more guidelines that are introduced, the more restrictions are placed on the person with disability and their family as to how they can best utilise the funds to meet their greatest needs.

*Q27. Should people be able to treat funding as ordinary income and do what they like with it? Should primary carers or other family members be able to pay themselves for providing care?*

A27. While individualised funding should not be viewed as just another form of income support (as is the case Carer Payments/Allowances or Disability Support Pensions), neither should government be too prescriptive about the uses to which the funding is put. For example, a family holiday with the family member with disability (and perhaps a travelling carer) may be more restorative and therapeutic for the family than placing the person with disability in a respite facility for the same period of time and at similar cost. Or a more expensive home in a suburb closer to needed services and good transport links may enhance the family's capacity and willingness to provide care for far longer than buying in home help and day support.

Due to a range of factors, a small number of family members are already directly funded by state governments to provide primary care to the person with disability. This is not dissimilar to Carer's Payments/Allowances, which are intended to compensate the carer for lost income due to being the primary carer and thus unable to work elsewhere. The concept is less about 'paying themselves' and more about enabling them to provide the primary (and probably higher quality) care without suffering financial disadvantage as a result.

However, it is important to avoid situations where circumstances lead to a primary carer being burnt out because they are providing all of the support. Paying them to provide that support does not alleviate the care demands and may increase social isolation for all members of the family. There are situations where a family member may require payment for support, however, this should not be the norm but should be subject to special consideration on a case by case basis.

*Q28. How would individualised funding work in rural and remote areas where service availability is poorer?*

A28. While the scope and extent of service availability is poorer in a number, but certainly not all, rural and remote areas Western Australian experience reveals that the lion-share of supports that people with disabilities and their families seek are practical, everyday supports. These supports are generally available in most communities. Extensive needs analyses of country people with disabilities

and their families before the introduction of Individualised Funding in country WA indicated that therapy services were the primary need. However, when they had access to Individualised Funding, and the discretion to spend it on whatever they wished, just 10% was spent by 362 surveyed country families, primarily parents, of people with disabilities on purchasing therapy and psychology services (Disability Services Commission, 1996). The comparative expenditure for 342 metropolitan families was only 2%. Amongst 176 people with disabilities surveyed, the figures were 3% for metropolitan based individuals and 1% for their country counterparts.

Instead, Individualised Funding in the control of families was mainly spent on in-home and out-of-home respite (42% overall: Metropolitan 28%, Country 47%), personal care (12%: M 14%, C 11%), aids and equipment (12%: M 12%, C 11%) and leisure support (12%: M 12%, C 11%).

Individuals with disabilities mainly spent their Individualised Funding on the following services (Disability Services Commission, 1996): live-in support (25%: M 34%, C 24%), leisure support (13%: M 13%, C 12%), employment support (11%: M 1%, C 16%), personal care (9%: M 11%, C 9%) and in-home and out-of-home respite (9%: M 7%, C 10%).

*Q29. Who would be responsible for monitoring individualised funding?*

A29. This question presumes that Individualised Funding needs to be monitored. 'Monitoring' often evolves into 'controlling' or 'managing' – especially when undertaken by public sector authorities or their agents. It would be far better to provide Individualised Funding recipients with access to a knowledgeable and competent service advisor (like a local area co-ordinator in WA or an options co-ordinator in the HACC system) who can assist them to determine their needs and how best to have those needs met.

Accountability could be managed via mechanisms such as third party viewing of discreet bank accounts set up to track spending or financial intermediaries providing acquittance statements.

*Q30. What would be the impacts of individualised funding on service providers and do these impacts matter?*

A30. The widespread implementation of a National Disability Insurance Scheme with Individualised Funding would increase the amount of funding accessible by service providers many times over. Any service provider that was unable (or unwilling) to grow and flourish in such an expanded funding environment is simply not offering the types of services that people with disabilities or their families want. As such, they should be allowed, and even encouraged, to wither and die.

*Q31. Are there ways other than individualised funding that empower people with disabilities and their families?*

A31. There is nothing more empowering than individualised services underpinned by individualised funding with primary control in the hands of people with disabilities and their families. Under individualised servicing, 'clients' become consumers – potent and able to exercise real choice. The old marketing adage 'The customer is always right' has no parallel sentiment in the service world of clients and patients. Only individualised funding coupled with individualised services has the potency to transform disability services from a supply-driven system (the client fits the service) to a demand-driven system (the service fits the consumer).



## **The nature of services**

*Q32. Are there any services not provided now that should be part of a national disability scheme?*

A32. The fewer limits and restrictions placed on how Individualised Funding can be spent by people with disabilities and their families, the less relevant or important this question becomes. With people with disabilities and their families in control of the funding, they will progressively seek out and utilise any services they deem they need (many of which will not have been predicted by service providers, professionals or government).

*Q33. What are the most important services, their costs, their likely demand and who would be the predominant users?*

A33. It is impossible to answer this question with any confidence because, never before, have so many people with disabilities and their families had free rein to purchase the services they need, rather than choose from a limited menu of services that providers happen to offer.

WA government research (Disability Services Commission, 1996) has previously revealed that the services most frequently purchased by 704 care giving families in WA were: respite support (42%), personal care (12%), aids and equipment (12%) and leisure support (12%) – accounting for 78% of all services purchased.

Services purchased by people with disabilities living outside the family home were: live-in support (25%), leisure support (13%), employment support (11%), personal care (9%) and in-home and out-of-home respite (9%).

*Q34. How should service providers be monitored and regulated with respect to quality, outcomes and cost effectiveness?*

A34. This should be managed through existing state/territory government quality assurance systems, which will need to be harmonised to ensure national consistency.

*Q35. How would services be structured to increase the likelihood of participation in work and the community?*

A35. There is already a network of some 250 DEEWR funded Disability Employment Services supporting some 60,000 people with disabilities to find and retain employment. There are a further 100 FaHCSIA funded Australian Disability Enterprises employing some 20,000 people with (mainly intellectual) disabilities. There are also several hundred state and territory funded day support programs for people with disabilities. Thus, there is already a network of close to 1,000 providers providing open employment, rehabilitation, sheltered employment and community access services operating around Australia. Many of these providers would have the capacity and willingness to grow to meet increased service demand. Others may not for reasons program preference, delivery cost, staff availability or service infrastructure. People with disabilities who receive individualised funding need only determine what type of services they want, who and where they are, and negotiate a service on a user-pays basis.

*Q36. Should all services be free or should there be scope for co-payments? To which services and/or people might a co-payment be applied? How would the size of co-payments be determined?*

A36. Under an individualised funding model, all services not currently provided to recipients of individualised funding would need to be paid for by the recipient. If a recipient is already receiving a service from a provider, they should be able to negotiate to top-up an existing service to increase its utility, intensity and value.

There is scope for co-payments under a national individualised funding system. However, provision for a co-payment must be according to individual's ability to pay and services should not be denied. There also needs to be adequate unit costings with additional allowances for distance, complex needs and transport.

*Q37. What should be the relative roles of specialist compared with mainstream services?*

A37. Mainstream services should be first choice services, but only if they can deliver needed services that are equivalent effectiveness, quality and utility of specialist services. Specialist services (be it schools, employment support, medical services, transport) can act to segregate people with disabilities from mainstream society.

*Q39. To what extent, if any, should people be able to cash-out the benefits from a basic service/appliance/aid (for example, a wheelchair that met assessed need) and use it as a part payment in purchasing a premium service (a more advanced wheelchair)?*

A39. To the extent that they wish, based on their unique insight into their own needs and preferences and the impact such a decision will have on their own lives (and ability to purchase alternative products or services with the funding they receive).

*Q40. How are service needs likely to change over time and how should that be accounted for in designing a long-term care system?*

A40. Many people with disabilities will experience increasing support needs during the course of their lives. Others may experience a reduction in support needs due to effective early intervention or consistency and suitability of current supports. The system should incorporate periodic reviews, especially at key transition points (infancy-to-school, school-to-work, work-to-retirement), along with the capacity for a funding recipient to initiate a review due to changing support needs or circumstances (e.g. loss of primary carer).

*Q41. What are the challenges for delivering expanded services in remote and rural Australia, including for specific communities, such as Indigenous Australians, whose needs vary?*

A40. There are a number of challenges that can arise when meeting the needs of individuals with disabilities and their families living in remote and rural Australia. There are increased costs associated with the delivery of support outside of the major metropolitan locations.

Travel costs can be significantly higher. This may relate to individuals and families seeking connection with programs and services and/or service providers travelling to the individual to provide direct support. There are also increased costs for individuals and families related to the travel required when having to attend appointments to see specialists, therapists, etc. as these are often in the larger rural towns or regional centres. Increased costs, due to higher unit costs of petrol, can be exacerbated by substantial increases in distances that are required to be travelled. Service providers may be required to replace vehicles more often than organisations working in the metropolitan centres, due to the increased distances travelled and the impact (wear and tear on vehicles) of travel required on unsealed roads.

Access to training can be more difficult and more expensive, especially if related to the more complex care needs or medically oriented training. Training may not be available in the more remote locations and paying for someone to travel can be significant especially when flights and accommodation are required.

Access to specialists can be limited, especially occupational therapists, speech therapists and psychologists. Support, training and personnel to meet the needs of people with complex and challenging behaviours can be difficult to secure.

The ability to employ family members, especially in more remote Aboriginal communities, can be a challenge if funding is not flexible enough to accommodate family members being employed. Ensuring the person with a disability has access to, and has direct benefit from; funding allocated to them can sometimes be a challenge in remote communities. Any program working with, or being administered by, an Aboriginal community needs to be a culturally sensitive and services need to be delivered by Aboriginal people from the appropriate skin groups.

Access to appropriate cultural awareness learning for organisations working with Aboriginal people can be difficult to identify and engage but is essential for any service working with Aboriginal communities.

There are issues related to the repair and maintenance of equipment. There can be additional costs associated with shipping equipment for maintenance and repair work and the potential challenges for the individual and family, resulting from the absence of their equipment, due to it being away for repair, etc. If equipment is essential, and the person cannot be without it, then the individual or family may be required to have a backup – this may be an additional impost on the family or service provider.

Access to, or investment in, communication technology can be a way of reducing some costs associated with service delivery and training in rural and remote locations.

People living and working in rural and remote locations have been historically resourceful and inventive when required to accommodate an individual's needs and are valuable resources.

*Q42. How could innovation be encouraged?*

A42. People with disabilities and their families have proven themselves to be very innovative in devising and securing services and support that meet their unique needs, circumstances and preferences - far more so than service providers, professionals and governments. The key to innovation is to give recipients of individualised funding the greatest freedom and discretion to find and secure the services and supports that best work for them.

They should also be encouraged, and perhaps resourced, to share innovative models and services with other people with disabilities, service providers, professionals and governments to demonstrate what is possible.

*Q43. How should the long-term care and support needs of individuals be assessed?*

A43. The eligibility determination and support needs quantification process will be crucial to the efficiency, effectiveness and overall integrity of a long-term care and support scheme. Thus, government needs to invest adequate resources in getting eligibility and support needs right. Such a system needs to be independent, accredited, closely connected with government and built onto existing assessment infrastructures (such as local area co-ordination in Western Australia), where practicable.

Assessors should be carefully selected, well trained, well supported, well remunerated and closely monitored to enable them to undertake comprehensive, face-to-face assessments. There should be provision within the process to enable people with disabilities or their families to complete a self-assessment, which will form part of the overall assessment.

There should be multiple levels of funding (at least five) to ensure that the amount of funding closely approximates actual support need. There should be an appeal process if the person feels that the funding level is inadequate.

There should be an automatic periodical review of support needs: perhaps every three years. There should also be capacity for funding recipients to initiate a review if needs or circumstances change significantly (e.g. death of primary carer, deteriorating condition). This may be limited to a maximum of one review between each periodic review.

*Q44. What are the appropriate features of assessment tools?*

A44. Focus on the person. Understanding of the person within their broader living context. Contribution of the person (and/or their family) to the assessment. Careful and comprehensive information collection. Opportunity to comment on preliminary assessment. Right of appeal.

*Q45. Should assessment gauge both eligibility and the extent of need in the one set of instruments, or should the assessments be distinct?*

A45. Either system could work.

*Q46. Should a nationally consistent tool be used (and what process would be used to achieve consistency quickly)?*

A46. Yes. Otherwise, people may move to different regions just to receive the most desirable assessment and benevolent allocation.

*Q47. What are the risks associated with different approaches and how can these is minimized*

A47. The assessment tool should not be materially different in the first case for reasons described in A46.

*Q48. Who should use assessment tools (GPs, specialist disability staff, specialists)? Who should employ or engage the assessor.*

A48. The federal or state/territory government should engage, pay, train and monitor the assessor. Any person who meets the comprehensive selection criteria should be able to undertake the assessments. Fees for undertaking assessments must be high to ensure that high quality assessors apply and take sufficient time in their determinations.

For reasons of consistency, the federal or state/territory government should engage, pay, train and monitor the assessors. Any person who meets the comprehensive selection criteria should be able to undertake the assessments. Fees for undertaking assessments must be high to ensure that high quality assessors apply and take sufficient time in their determinations.

*Q49. How would the accuracy of assessments and the performance of assessors be gauged?*

A49. There are many robust techniques for determining reliability and validity of assessment instruments. Any university with a good psychology department, as opposed to one of the major accounting firms, should be able to undertake this role.

*Q50. On what basis should beneficiaries be reassessed? How should assessment processes take account of changes in life circumstances?*

A50. Many people with disabilities will experience increasing support needs during the course of their lives. Others may experience a reduction in support needs due to effective early intervention or consistency and suitability of current supports. The system should incorporate periodic reviews, especially at key transition points (infancy-to-school, school-to-work, work-to-retirement), along with the capacity for a funding recipient to initiate a review due to changing support needs or circumstances (e.g. loss of primary carer).

*Q51. How would data from assessment be used? (for example, should it be available to a range of service providers?)*

A51. People with disabilities and their families are entitled to privacy. There is no clinical or therapeutic case for this information to be distributed to service providers. Widespread distribution may lead to some people with disabilities and their families (who may be vulnerable or initially unsure of how to apply their funding) being solicited by services providers keen to expand their services.

There should be the option for brief demographic and other relevant information (comparable to the individual needs assessment from the Disability Services Commission in WA), made available on an “opt in” basis, so that people don’t have to tell their story to multiple people and providers.

A level of information comparable to the individual needs assessment from the Disability Services Commission in WA is practical and useful for agencies to be able to select and develop the right staff match and the right services. However, the information should be owned and managed by the family.

*Q53. What role would mainstream services play in any national disability scheme (such as coordination and facilitating access)?*

A53. Service co-ordination and/or service delivery would be reasonable and acceptable roles for mainstream services to play alongside specialist services.

*Q54. How do you prevent cost shifting between services inside and outside of the scheme?*

A54. There are many people with disabilities around Australia who are provided with services through the various state and territory governments. Whilst some of these funds may be individualised, most would be delivered to providers in the form of block grants (Western Australia being the exception). Services that people with disabilities currently receive will need to be individually costed (i.e. disaggregated) and that amount netted off their individualised funding payments until such time they no longer receive services from that provider – at which time those funds would be built back into their funding allocation. Some current service recipients may be found to be receiving services that are in excess of their assessed support needs. These existing arrangements should be grandfathered so as not to create anxiety about the new funding scheme potentially leading to a reduction in services to these people.

*Q55. Where services remain outside a long-term care and support scheme, how can service delivery be best coordinated?*

A55. This question presumes that the scheme would proscribe certain services. If no services are specifically proscribed, this question would not have to be considered.

*Q58. How should disability associated with catastrophic injuries be addressed?*

A58. Disability arising from catastrophic injuries should be addressed in the same manner as lifelong disability.

### **How much is needed?**

*Q65. What is the magnitude of funding needed for a national disability scheme?*

A65. The Productivity Commission has previously reported that 80% of the care and support provided to people with disabilities is informal. That is, it is provided gratis by family, friends and volunteers. Thus, the upper limit could be expected to be five times the current federal, state and territory expenditures on formal services for people with disabilities. However, anecdotal evidence from individualised funding in WA suggests that people with disabilities and their families prefer the convenience and informality of unpaid supports to formal services where that support can be delivered adequately and sufficiently. Traditional formal services (those that usually provide congregate care and support) can be intrusive, programmatic, inconveniently scheduled, and insensitive to individual needs and preferences.

It is the experience of WAIS members (who predominately provided individualised, community-based services) that building services into existing community infrastructure and services provides for greater cost efficiency in service delivery. Under these types of arrangements, the actual limit might be only two to three times what is currently expended in formal service delivery.

*Q67. How should unmet demand be measured and what is its size in value and person terms? Where are unmet demands greatest?*

A67. Data on unmet need for people with disabilities has been collected in jurisdictions around Australia for at least 15 years. This data has been assembled via direct consumer report, service provider waiting lists; government needs analysis surveys and ABS data sets. Unmet need can be an unhelpful measure in that, as soon as the first cohort of people with unmet need have their needs met, they will be replaced by a new cohort – whose needs may not necessarily be materially less than the first cohort. By way of example, the Disability Services Commission in WA embarked on the development of a Five Year Business Plan (the corresponding author of this submission co-ordinated the development and successful submission of this \$125 million dollar plan to the WA government). The plan identified 254 people with unmet accommodation support needs. A key outcome for government through funding this plan is that it would eradicate unmet need. While the plan was largely successful in meeting the needs of those 254 known people, they had been replaced by a similar number of previously unknown people with unmet need by the end of that five-year period.

*Q68. What are the future levels of unmet demand associated with the current system, and with what implications for future funding?*

A68. For the reasons outlined in A67, this is very difficult to quantify.

*Q69. What are the practical implications of an 'entitlement-based system' for the design of a scheme, its sustainability and for budget management by governments? How could costs be contained?*

A69. A similar question could be asked of the Medicare scheme. The Whitlam and all successive governments have committed to funding an entitlement-base (universal) medical care scheme. A levy was established at the outset, which has only had to be adjusted from 1% to 1.5% over the course of 35 years. A similar outcome might be reasonably anticipated with a universal disability insurance scheme.

### **Financing options**

*Q70. What would be the best way of financing a national disability scheme and why? What are the strengths and weaknesses of alternative financing arrangements, including 'pay-as-you-go' and funds that take account of future liabilities?*

A70. A Medicare style levy (that may be of the order of 0.8% rising to 1% in later years) would be the most appropriate form of financing the scheme. The larger Medicare scheme does not take account of future liabilities, but seems to have operated successfully for 35 years: even in the face of an ageing population, burgeoning health costs and even more rapidly escalating pharmaceutical outlays.

### **Workforce issues**

*Q83. How can workers be attracted to the industry? What role should government play in this process?*

A83. Experience of individualised services providers in WA is that many of the support people that they, or people with disabilities that they support, engage do not come from the traditional labour pool. Many are word-of-mouth contacts via family and friends of the person with disabilities or support people already engaged in providing care. In other words, they are outside the normal labour market pool and are not necessarily even seeking employment.

Government has a role to play in this process in ensuring that adequate funds are available to properly remunerate support people. Government also has a role to play in ensuring that training packages are properly constructed to deliver the type of training that support people might need to support people with disabilities in their own homes and the community. Such training should not be mandatory and neither should there be any minimum qualification requirements, as many of the best support people do not have and will not wish to undertake formal Certificate level courses – and, in many cases, such training will not be needed to provide competent care and support.

*Q84. What type of skills and workers are required?*

A84. The support needs of people with disabilities are so vastly different that there is no common skill set that all support people would need to possess. Indeed, the imposition of a standard minimum skill set would only serve to exclude many potential quality carers, leaving many people with disabilities unable to recruit support people. Many people with disabilities are more than capable of making their own judgement about whether a candidate is suitably equipped to meet their support needs and should not be prevented from choosing the person they consider most suitable. The experience of many Individualised Funding providers is that the majority of the support people engaged directly by people with disabilities do not have formal qualifications, yet they are

rated more highly as a group of carers by people with disabilities than those who do have formal qualifications.

*Q85. What role should government play in upgrading the skills and training opportunities available to workers?*

A85. Government should ensure that nationally competencies in the areas of disability support reflect the diverse needs of people with disabilities, not just those who are supported in congregate care facilities. Government should provide special incentives to both public and private RTOs to develop and deliver high quality and contemporary courses for interested current or prospective support people.

What is more even important than skills training is the pre-eminent role of values in choosing the right support people and how these can be further developed through training to enhance a person-centred approach.

Additional training modules that should be added to national disability training packages include: advocating with participants and their families; inclusive attitudes and skills for mentors and support workers involved in community facilities; and addressing specialised complex needs of individuals.

*Q88. How long would it take to build up the required workforce?*

A88. Any such workforce is likely to be far more casualised than would be the case with more formalised services supplied by service providers. The demographic of the workforce is also likely to be wider than the traditional service provider controlled disability workforce. Neighbours, friends, students, people from culturally and linguistically diverse backgrounds and refugees are likely to figure more prominently in the 'workforce' assembled by people with disabilities and their families who are arranging and purchasing their own services. Thus, they will be tapping into areas where there is higher incidence of unemployment and under-employment: a positive for overall participation rates and the broader economy.

*Q89. Are there particular skill bottlenecks that need immediate attention?*

A89. Skill bottlenecks may arise in areas such as: first aid; manual handling (lifting and transferring); occupational health and safety; social skill building; supporting people with complex and challenging behaviour; utilisation of peg feeds and catheters; bowel care; skin pressure care.

*Q90. What role could volunteers and workers in mainstream services play?*

A90. Volunteers are already heavily engaged in the provision of care and support to people with disabilities: either through volunteer organisations or individual involvement. Volunteers represent a component of the 80% of support that people with disabilities currently derive through informal arrangements as opposed to formal services. It is possible that volunteering may reduce as people with disabilities and their family find themselves with the financial resources to pay for needed services.

The vast majority of services that people with disabilities and their families need and will seek are not specialist in nature (see A28 and A33) and, thus, mainstream services will be well positioned to extend their services into the disability arena.



*Q91. What is the appropriate level of training required before commencing work in the industry? Should any existing certification requirements be altered to reduce obstacles to people working in the disability sector?*

A91. Where people with disabilities are living in congregate care arrangements, there is a case to be made that they should attain some minimum level of qualification (linked in some way to an appropriate national training package or packages). This is because the disability profile and needs of the people who are congregated are likely to be diverse and require a range of knowledge and skills to properly respond to their respective situations and needs.

This is not the case with people with disabilities and their families who choose an individualised service for themselves or their family member. There may be several different support people involved – each of whom brings different skills (and it may be unnecessarily duplicative to have every support person possess the same skills). The person with disabilities or their family may be quite capable of directing the performance of any support people themselves and ensuring that the needed supports are provided in an appropriate manner. Requiring every support person to have some standard minimum level of qualification (whose real value is open to debate in any event) in these individualised arrangements will only serve to severely restrict the potential candidate pool and force people with disabilities to compete with established service provided in an already tight segment, and likely to become tighter, of the labour market.

*Q92. What role is there for national accreditation?*

A92. For reasons outlined in A91 above, the consideration of any national accreditation system should be limited to congregate care (be it accommodation, respite or day support programs), allowing people with disabilities and their families seeking individualised support arrangements the greatest freedom, flexibility and discretion to select their own support people from the widest possible pool of candidates.

### **Appraising costs, risks and benefits**

*Q116. How much do various services cost (for example, attendant care, accommodation, day centres), and what pressures are on these costs?*

A116. Experience in WA, where several thousand people with disabilities and their families have had ongoing access to Individualised Funding (ranging from several hundreds to tens of thousands of dollars per year) are more proficient than formal services providers (government and non-government) in procuring needed services in an efficient and cost-effective manner. They see the Individualised Funding they receive as a finite and precious resource and are loathe to spend it wastefully.

Cost pressures will arise for them if they have to compete with government and non-government providers for the same limited pool of support people: which will happen if the scheme requires all support people to possess a minimum level of qualification.

*Q118. How should unmet needs be measured?*

A118. Data on unmet need for people with disabilities has been collected in jurisdictions around Australia for at least 15 years. This data has been assembled via direct consumer report, service provider waiting lists; government needs analysis surveys and ABS data sets. Unmet need can be an

unhelpful measure in that, as soon as the first cohort of people with unmet need have their needs met, they will be replaced by a new cohort – whose needs may not necessarily be materially less than the first cohort. By way of example, the Disability Services Commission in WA embarked on the development of a Five Year Business Plan (the corresponding author of this submission co-ordinated the development and successful submission of this \$125 million dollar plan to the WA government). The plan identified 254 people with unmet accommodation support needs. A key outcome for government through funding this plan is that it would eradicate unmet need. While the plan was largely successful in meeting the needs of those 254 known people, they had been replaced by a similar number of previously unknown people with unmet need by the end of that five-year period.

*Q125. To what extent could a new scheme produce cost savings (or other offsets) and what design of the scheme would be likely to maximise these without limiting service delivery?*

A125. Cost savings are most likely to be maximised by a) placing control of the funds in the hands of people with disabilities and their families b) allowing people with disabilities and their family maximum discretion about what supports they purchase, how they are delivered and who delivers them, and c) providing them with access to a network of service consultants or brokers who can, for a reasonable fee, assist them to identify, locate, engage and monitor needed supports.

*Q126. What are the benefits from a new disability care and support scheme? Which are most important? Who would benefit most from a new scheme? Where would additional resources be best spent? What level of funding maximises the gains from a new scheme?*

A126. There is strong evidence that, for very many people with disabilities, the more early and intensive the intervention, the less services will be required in the longer term. A well-designed and responsive national disability insurance scheme will enable early intervention services to be put in place in a timely manner, which will mean that less families will collapse under the burden of care, less people with disabilities will need to be accommodated in crisis accommodation, less segregated and expensive accommodation facilities will need to be built, and less beds in hospitals and nursing homes will be inappropriately filled by younger people with disabilities. It will also mean more people with disabilities will have independent living skills, more time would be available to plan individualised community-based living solutions and formal informal supports could be retained and enhanced.

All people with significant and profound disabilities (whenever or however acquired) of an enduring nature will benefit from the scheme – especially those who are not currently in receipt of services and those who are receiving inappropriate or inadequate services.

The additional resources will be best spent meeting the self-determined needs of eligible people with disabilities – as opposed to being placed under the control of services providers who may or may not develop or expand the services that people with disabilities most need and want or may not deliver them in a way that meets their individual circumstances or preferences.

The level of funding that will maximise the gains from the new scheme will be the aggregated funding provided to all eligible people with disabilities and their families that was determined through a proper process of individual needs identification that is accurately costed by a competent independent assessor.

## **Mental health has a fundamental place within the context of disability care and support reform**

The prevalence of mental illness is high in Australia and other western countries. About one in five adults will experience symptoms of mental illness in a 12 month period - this means that 2.4 million Australians had at least one condition during the last year. The most prevalent mental health problems are anxiety-related and depressive disorders. Approximately ten per cent of the population is affected by an anxiety-related disorder in any one year, and six per cent of the population experience depressive disorders in a year.<sup>1</sup> Psychotic illnesses such as schizophrenia and severe mood disorders are less common, but are usually very disabling. Yet only one third of sufferers receive help from health services – a staggering 65 percent of sufferers battle their disorder alone or only with the help of family.<sup>2</sup> Mental illness afflicts more Australians than almost all other health disorders. Only cancer and heart disease impact more people.

Mental illness has become the largest cause of disability in Australia. With mental health disability affecting an estimated 25% of people with disability needing constant or frequent support<sup>3</sup> it's time to include the care and support of people with mental illness in the conversation about reform.

The employment participation rate of people with a diagnosed mental illness which warrants Disability Support Pension is lower than for other disability groups. Illnesses such as Schizophrenia and others incorporating psychosis tend to affect people in their youth leading to years of lost productivity and quality of life. People with mental illnesses are also over-represented in the justice system. With the right sort of assistance recovery is possible; however the assistance currently available is failing many of these young people. They are more likely to suffer from stigma than many other groups, often because of the way in which they are commonly represented in the media and in film and popular culture.

There is a gap between the kinds of support services offered by mobile, psychosocial case management models which support recovery and crisis intervention and the leap forward into employment services, where the expectation is that the recovery will be nurtured in the workplace. In reality, work can be stressful and demanding, and the idea that entry-level work is less stressful and demanding than skilled work is possibly a stereotype. Often entry-level work is demanding in terms of negotiating the social milieu, and demanding in terms of productivity required, and demanding in terms of understanding and tolerance of supervisors. Entry level jobs often start earlier than other jobs and are often more physically demanding. If they are boring, they require a high level of concentration to maintain productivity.

Although people with mental illness can benefit from work, we also need to understand what is at stake and what might be lost. One thing is the space to retreat from the demands of the world, and from the situations that increase anxiety and trigger relapse. While people with mental illness are often more motivated than many others to go to work as it offers some sense of normality and pride, they are also pulled away from going through fear of not measuring up. Because of the nature of the disability this can often be greater than for other groups (depending upon the diagnosis), so an easing back into the community is often needed. Ideally psychological monitoring and assistance should also be made available for graduated return to work and support. The current funding system for Disability Employment Support does not necessarily support return to work for people with mental illnesses as well as it does for people with other conditions.

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<sup>1</sup> National Survey of Mental Health and Wellbeing 2009

<sup>2</sup> Mental Health Council of Australia. (2010). *Mental Health Fact Sheet*. Retrieved from: <http://www.mhca.org.au/documents/AboutMentalHealth/FactsonMentalHealth.pdf>

<sup>3</sup> DIG (2009b), Productivity Commission Issues Paper Disability Care and Support Figure 1

## Disability Care and Support- Issues Paper Response

What needs to be created? More opportunities for learning and practicing work skills in a supportive environment. More opportunities for developing skills that are valued and thus help to overcome any stigma associated with the diagnosis. More government vacancies that are made available to people with a diagnosed mental illness. More specifically targeted groups to learn skills for managing stress in the workplace, and more leadership and commitment by government in creating government departments as both productive and mentally healthy places for employees, and for such departments to act as exemplars for private industry.

People with mental illness continue to experience significant discrimination and stigma associated with their illness. PHCS continues our journey to see people we support and their families:

- welcomed by communities who embrace differences and recognise gifts, attributions and strengths before illness, deficits and dysfunction;
- move from isolation and vulnerability to be able to access a range of formal and informal supports

People with an intellectual disability and mental illness (dual diagnosis) often have complex and high support needs and are in need of improved access to a broad range of supports.

There is some relationship between the nature and the extent of disability, to the frequency of need for assistance with core activities. "People with intellectual disability were the most likely to need assistance six or more times a day."<sup>4</sup>The effect of caring for a person with intellectual disability on the carers' physical and mental health is well documented.

Two per cent of the Australian population have an intellectual disability and the prevalence of mental illness in this population is 30-50 per cent, the equivalent of at least 100,000 people. Their needs are often ignored because they fall between the gaps. Often the two disorders are treated separately or people are only referred onto a specialist service when a holistic approach to a person's recovery is taken.

In practice we have found it challenging to provide support to people with significant mental illness and an intellectual disability. For example one of these people, a woman called Maria continues to reside in Graylands hospital and has done so for the 3 years we have been funded to support her. The issues surrounding her transition to the community are complex. Despite the challenges we have some 'good news' stories to tell about our journey in supporting people with complex mental illness and disabilities. Sarah's story is indicated below:

***Janice (mother) cares for Sarah (daughter with mental illness and disabilities). When RHCS met Janice she was felt depressed and had difficulty coping with Sarah's challenging behaviours, the withdrawal of support by a service provider in Northam over OSH concerns, and rejection of an application for funded assistance. A relationship of trust was established by RHCS with Sarah to support development of goals and facilitate progress towards achievement. Sarah now has a more positive approach, has membership at a local gym and Janice is also attending (supported by CCRC). Both mum and daughter also attend the local pool daily for 30-45 minutes. Through the BIG Plan sessions, Janice was able to identify her gifts and talents and now is starting her own business from home with the support and partnership of her daughter. RHCS has assisted Janice with funding applications and recently approval was received for up to 20 hours a week respite and ATE funding for Sarah at home.***

For people with dual diagnosis as well as for every person who suffers with a mental illness, and hopes for recovery, mental illness should be part of the disability care and support discussion.

### **The PHCS Journey in Consumer Directed Support**

Strategically, we aim to assist people in the community of WA to be in control of their lives, connected with family and community, regardless of circumstances, by recognizing that each person is unique and working with them to develop the supports they need. Our work is underpinned by the person centred approach.

PHCS is strongly committed to thinking and working in a person centred way. In this work, we support people to:

- Make choices and decisions for themselves
- Grow and develop in their relationships
- Be present and participate in the community
- Have valued roles and contribute
- Develop their talents, interests and abilities

PHCS provides support to people across the aged, disability and mental health sectors. We have been successfully providing support to people receiving individual funding in our Disability services programs for many years. In the last 4 years, PHCS has been supporting some people with individual funding who elect to "share manage" their support. That is, that PHCS works with people who have individual budgets to decide what types of support they would like to pursue and helps people secure those supports, whether they are PHCS supports or natural supports known to the person, to develop an individual plan of support which is unique to each person. We currently have infrastructure in place to support this work including a handbook called "Managing Your Own Supports" for people with individual funding. We also have reporting mechanisms for individuals managing their own budgets (monthly statements) as well as the ability to provide acquittal information to the funder. People who manage their own supports are integrated into our organisational structure and supported by Coordinators who are quite familiar with consumer directed support. Whether a person is frail aged, has a disability or a mental illness, people who have their own budget for support are integrated into the current organisational flow.

Self directed support innovations are becoming more prevalent internationally as well, and PHCS has been keeping a watching brief on and looking at innovations from outside Australia. An interesting innovation from the UK is the website [www.shop4support.com](http://www.shop4support.com) where people can shop for support they need across a range of areas. There is also a "planning my support" feature which allows people to think and plan the support they might need based on their budget and a helpful link to [www.supportplanning.org](http://www.supportplanning.org).

PHCS understands that people want to be in control of the support that they receive and that providers become frustrated with the limitations of available options.

#### *Shared Management*

Over the past 4 years we have been developing our capacity to Share Management of funding with people and families so that they have greater control of their supports and funding (the

person/family manage and employ their own workers directly). With PHCS's commitment to work in partnership with people so they have greater control of their supports we have built on our learning and further refined our systems and resources for Shared Management in recent months. In particular we have developed a manual "Managing Your Own Support" for families. The Manual was initially developed by Mamre (a Queensland organisation that has done considerable work in family led and managed supports) and we have adapted it for our work in Western Australian.

People who share management take up many of the responsibilities, including recruiting and paying staff, managing their support team and roster. PHCS supports people to manage their funds well and meet the funding body's requirements. Some of the specific services we provide include:

- Assistance with planning to get the best possible supports and outcomes. This planning process can be reasonably simple to do for some people but others need more assistance.
- Establishing the budget, funding plan and documenting agreements.
- Meeting with the person at least every six months to review the arrangements, assist them to revise plans, ensuring everything is progressing well and meeting the funding body's standards
- Problem solving if issues arise along the way
- Reviewing and processing Acquittals of expenditure monthly
- Monitoring expenditure against the funding available quarterly
- Providing periodic financial statements
- Reporting expenditure and hours to the funding body annually; and when required
- Reporting serious incidents to the funding body.

Currently we charge program management fees between 10% and 15% to people for these services. Where people also use PHCS support staff, additional fee for indirect coordination and staffing costs is charged. People who manage their own support are very mindful of the costs they incur and are very reluctant to pay for services they don't see as being worthwhile. In the future we will need to have more accurate information about the cost of providing these services to assist with communicating with people and ensure viability.

PHCS is a leading organisation in shared management. As of the end of April, 40 families share management, most with IFS and PSO/ATE funds.

### **Conclusion**

PHCS/RHCS and the many people who have made a contribution to this submission appreciate the opportunity to make comment on Disability Care and Support. We look forward to the draft report in February and further opportunity to contribute to the discussion.