ABOUT MY PLACE

My Place was established in 1996 in response to a need for more flexible and individualised approach to provide support for people with disability in Western Australia. Until that time Western Australians with disabilities in receipt of Disability Services Commission (DSC) funding had few options if they wanted to live in a home of their own, wherever they chose, with whomever they chose, in a manner they chose and supported by carers they chose.

My Place supports people with varying disabilities including: intellectual disability, cerebral palsy, multiple sclerosis, autism, muscular dystrophy and spinal injury. The 230 people with disability that My Place currently supports range in age from 10 to 72 and live around the Perth metropolitan area or in the South West of WA.

My Place exclusively provides individualised services to people with disability. The majority of the individualised funding received by My Place is provided by the WA Disability Services Commission. Individualised funding is also received from the Public Trustees in WA and NSW (for accident compensation recipients), the Transport Accident Commission in Victoria (for accident compensation recipients), and the WA Department of Child Protection for wards of the state with disability.

In all of these cases My Place operates as the funding holder, working with people with disability, their families and guardians to purchase the services that they need and ant.

My Place currently provides accommodation support to 148 people. Approximately half are supported to live in their own home (which they may be renting or purchasing). A quarter, usually younger people, are supported to live with a host family. The remaining quarter are supported to remain in their family home. My Place is committed to supporting people with disability to live in homes that are safe, comfortable, affordable, convenient, and in a location of their choice.

My Place's approach to supporting people to live in the community is personalised, creative, responsive and flexible. This is evident in My Place's individualised planning process, known as 'My Plan'. My Plan is about sharing important information so the people in the life of a person with a disability can develop a clear understanding of who they are and what their actual support needs are. My Plan is also about the future and supporting people with disability to achieve their dreams and aspirations so they can live the life that they want. My Plan is regularly updated so that people with disability continue to receive the support they need to enjoy a good life in the present and even better life in the future.

My Place provides community-based day support to 82 people with disability to participate in daily community life. People with disability and their families are assisted by My Place to choose a range of community based activities. Activities typically include some combination of active recreation, passive recreation, personal development, further education and voluntary community work. My Place provides support to people with disability to undertake these activities.

People with disability who are allocated individualised funding have a range of options as to how they use their funds and how their services are provided. Anybody who uses My Place's services can choose any of the options described below and may move from one option to another as their needs and preferences change.

SHARED MANAGEMENT involves people with disability and/or their families managing and co-ordinating their own services, but having an approved organisation such as My Place administer the funds. In other words, people with disability design and run the own service, but engage My Place to:

- ensure that all legal requirements are met;
- pay the carers and other support people;
- calculate PAYG tax and submit it the Australian Tax Office (ATO);
- arrange and pay public and products liability insurance;
- arrange and pay workers' compensation;
- calculate and pay superannuation;
- submit all necessary documentation to the ATO;
- hold and administer the grant funding; and
- acquit the funds back to DSC or other funding body.

An amount of 15% of the individualised funding is charged by My Place to administer the option.

Under Shared Management, people with disability can exercise maximum control over the direct care funding allocated to them. My Place offers several ways for people with disability, or family member, to engage their own carers under Shared Management. One way is to arrange apply for a Withholder Payer Number (WPN) through the ATO, which then establishes them as a legal entity that can employ and pay staff in their own right.

An advantage of people with disability (or a family members) being the employer is that, under certain conditions, carers can be employed under 'private and domestic' arrangements which offers greater flexibility in carer pay levels, conditions and hours of work as the carer is not deemed to be an 'employee' in the traditional legal sense.

Another option under Shared Management is for the person with disability (or family member) to engage an independent contractor to provide the needed supports. The advantages of using independent contractors is that the person with disability has control over who the carers are, the flexibility to adjust supports to suit changing needs and interests, and fewer legal responsibilities, as the carers are not employees.

A third option under Shared Management is to incorporate a 'micro-agency' around the person with disability. The micro-agency usually has a small Management Committee made up of family, friends and other interested people.

The micro-agency receives the direct care funding from My Place and co-ordinates needed services. My Place arranges an Australian Business Number, prepares and submits BAS statements to the ATO and provides all other finance and administration services. An advantage of a micro-agency is that it can receive funds from other sources, such as a family estate or trust to extend the amount of direct care.

SHARED CO-ORDINATION involves people with disability and/or their families employing their own support people (as in Shared Management above), but having My Place administer the funds and co-ordinate all aspects of the service. In other words, people with disability design their own service and employ their own carers, but engage My Place to:

- help design the support package;
- help recruit, train and supervise the carers;
- pay and insure the carers;
- ensure that all legal requirements are met;
- arrange and pay public and products liability insurance;
- arrange and pay workers' compensation;
- calculate and pay superannuation;
- collect and submit PAYG tax;
- submit all necessary documentation to the ATO;
- administer the grant funding; and
- acquit the funds back to DSC or other funding body.

An amount of 15% of the individualised funding is charged by My Place to administer the option.

Under Shared Co-ordination, the person with disability allocates a further $8,250 per year from their direct care funding to pay for a Service Co-ordinator from My Place to help design the support arrangements and recruit, train, supervise and support the carers.

The main advantages of the Shared Co-ordination arrangement are that people with disability are able to employ carers far more flexibly that My Place can (this includes overnight care arrangements). People with disability also retain maximum control, as they are the employer of their own carers. However, everything legally required of them as an employer is done by My Place and the carers are monitored and supervised by a My Place Service Co-ordinator.

PROVIDER MANAGEMENT involves having My Place administer the funding on behalf of the person with disability, co-ordinate their services and employ their carers. In other words, engaging My Place to:

- design the support package;
- employ and supervise the carers;
- pay and insure the carers;
- collect and submit PAYG tax and superannuation;

- submit all necessary documentation to the ATO;
- administer the grant funding; and
- acquit the funds back to DSC or other funding body.

An amount of 15% of the individualised funding is charged by My Place to administer the option.

Under Provider Management, the person with disability allocates a further $8,250 per year from their direct care funding to pay for a Service Co-ordinator from My Place to help design the support arrangements and recruit, employ, train, supervise and support the carers.

The advantages of the Provider Management arrangement are that everything is done by My Place (removing any hassles associated with individualised support arrangements) and carers are employed and supervised by a My Place Service Co-ordinator.

Further information about My Place is available from its web-site at www.myplace.org.au or contacting:

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RESPONSES TO SELECTED QUESTIONS IN DISCUSSION PAPER

6 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'. Clearly, there are growing number of 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. Equally, 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.

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. 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 not be as well served by the new scheme, and 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. The scheme should apply to both existing and future disabilities.

7 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. The extent to which people with disability 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.

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. Drawing down future entitlements for current services could be difficult to manage, especially if the escalated services became a new benchmark below which the person with disability claimed that they could not be adequately supported. It would be wiser to review the current level of payment to assess its adequacy and conduct future reviews to reassess continuing adequacy. However, it might be useful to provide a small amount of drawdown against future years (e.g. to help fund capital and equipment purchases or occasional holidays). It is suggested that this be limited to 10% from any forward year and no more than five forward years in total. This would limit any total drawdown from future years to 50% of total annual funding. Similar restriction may also need to be placed on unspent funding from future years to minimise excessive hoarding.

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 disability (although there is an uninformed contrary view abroad amongst a number of service providers who do not operate Individualised Funding services).

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 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 whither and die.

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 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.

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 disability and their families seek are practical, everyday supports. These supports are generally available in most communities. Extensive needs analyses of country people with disability 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 disability 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 disability 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.

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

A30. The widespread implementation of an 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 disability 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 Funding with primary control in the hands of people with disability and their families. Under Individualised Funding, ‘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 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).

8 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 disability and their families, the less relevant or important this question becomes. With people with disability 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 disability 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 caregiving 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 disability 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 disability to find and retain employment. There are a further 100 FaHCSIA funded Australian Disability Enterprises employing some 20,000 people with (mainly intellectual) disability. There are also several hundred state and territory funded day support programs for people with disability. 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. Most of these providers would have the capacity and willingness to grow to meet increased service demand. People with disability 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.

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 disability 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 disability 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).

Q42. How could innovation be encouraged?

A42. People with disability 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.

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.

Whatever, the structure, the key to its success will lie in the competency of the people who are undertaking the assessment and the time that they are permitted to get to know the person, their circumstances and their needs.

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 be 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.

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 disability 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 disability and their families are entitled to privacy. There is no clinical or therapeutic case for this information to be distributed to service providers. This may lead to people with disability and their families (who may be vulnerable or initially unsure of how to apply their funding) being harassed by services providers keen to increase their revenues.

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 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 for 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.

9 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 My Place that building services onto 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 disability 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.

10 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.

11 Workforce issues

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

A83. My Place's individualised funding and services experience 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 disability 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 disability unable to recruit support people. Many people with disability 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 disability do not have formal qualifications, yet they are rated more highly as a group of carers by people with disability 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 disability, 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.

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

The vast majority of services that people with disability 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 disability 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 disability 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 disability 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 disability 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 disability 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.

13 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 disability 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 disability 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 disability and their families b) allowing people with disability 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 disability, 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 disability will need to be accommodated in crisis accommodation, less segregated and expensive accommodation facilities will need to be built, less beds in hospitals and nursing homes will be inappropriately filled by younger people with disability, more people with disability 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 disability – as opposed to being placed under the control of services providers who may or may not develop or expand the services that people with disability 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 disability and their families that was determined through a proper process of individual needs identification that is accurately costed by a competent independent assessor.

SUBMISSION ENDS