Inquiry into Long Term Disability Care and Support

People with Disability Australia (PWD) Submission to the Productivity Commission

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People with Disability Australia Inc

Contact Details

Michael Bleasdale
Executive Director
People with Disability Australia (PWD)
52 Pitt St Redfern NSW 2016
Email: michaelb@pwd.org.au Phone: +61 2 9370 3100

People with Disability Incorporated

Registered Office Addresses
Postal Address:
PO Box 666
Strawberry Hills NSW 2012

Australian Business Number (ABN)
98 879 981 198

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1. Introduction

The Australian Government has asked the Productivity Commission to undertake a public inquiry into a long-term disability care and support scheme.

Amongst other things, this inquiry will examine:

- how a scheme should be designed and funded to better meet the long-term needs of people with disability, their families and carers
- how to determine the people most in need of support, the services that should be available to them, and service delivery arrangements
- the costs, benefits, feasibility and funding options of alternative schemes
- how the scheme will interact with the health, aged care, informal care, income support and injury insurance systems
- its impacts on the workforce
- how any scheme should be introduced and governed
- what protections and safeguards should be part of the scheme.

The organisation making this Submission is People with Disability Australia (PWD).

This Submission uses the experience and strength of PWD to provide detailed recommendations on how specific aspects of the proposed long-term disability care and support scheme should work, and includes a methodology of how these recommendations came into being.

PWD established a Project Team to coordinate this submission, the members of which have extensive experience in the area of disability services and advocacy, and who have a particular focus on the application of human rights in a disability context.
The Project Team are highly skilled in policy formation, with knowledge grounded in extensive practice, empirical research, experience in research and consultation, and expertise in the application of human rights.

Writing this Submission required widespread consultation with the sector within a short period of time. PWD’s success in organising and managing these consultations is testament to the organisation’s capacity to effectively create a unified summation of different viewpoints.

For this submission, PWD’s contact with the peak body and advocacy sector across Australia and internationally, together with its cross-disability focus, placed us ideally to undertake meaningful consultation within the timeframe provided. The knowledge that PWD already has about disability care and support options means that, along with the results of the consultation process, this submission is a thorough, accurate and relevant expression of the aspirations and recommendations of people with disability as relevant to this inquiry.

2. Organisational Background

People with Disability Australia Incorporated (PWD) is a national disability rights and advocacy organisation. We exist within the international human rights framework and provide a number of activities, which include individual, group and systemic advocacy, complaints handling, information, education and training.

Individuals with disability and organisations of people with disability are our primary voting membership. We also have a large associate membership of people and organisations committed to the disability rights movement.

We were founded in 1980, in the lead up to the International Year of Disabled persons (1981), to provide people with disability with a voice of our own. We have a fundamental commitment to self-help and self-representation for people with disability by people with disability.

We have a cross-disability focus – membership is open to people with all types of disability. Our services are also available to people with all types of disability and their associates.

We are governed by a Board of Directors, drawn from across Australia, all of whom are people with disability. We employ a professional staff to manage the organisation and operate our various projects. A majority of our staff members are also people with disability.

We are part of an international network of disabled people’s organisations through Disabled Peoples International.

We are a non-political, non-profit, non-governmental organisation incorporated under the Associations Incorporation Act 1984 (NSW).

Our activities are supported by substantial grants of financial assistance from the Commonwealth and New South Wales Governments, as well as a growing number of corporate and individual donors. This financial assistance is acknowledged with great appreciation.

3. PWD’s Knowledge and Experience

PWD conducts a range of activities, including individual and systemic advocacy, and the operation of the Complaints Resolution and Referral Service (CRRS) and the National Disability Abuse and Neglect Hotline (the Hotline) on behalf of the Australian Government’s Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

PWD has a NSW, national and international focus, and conducts significant work developing the capacity of disability organisations in the Asia-Pacific region.

PWD was instrumental in Australia’s involvement in the development of the UN Convention on the Rights of Persons with Disabilities (CRPD), and committed its resources to bringing this to fruition at a time when there was little support from the Australian Government.

In relation to this submission, PWD takes pride in representing the many voices of people with disability to bring a unique, yet crucial, perspective to this Inquiry. PWD is an actively inclusive organisation with:

- a strong affirmative action policy in relation to the employment of staff with disability. Of its over 40 staff over 50% are persons with disability.

- a range of strategies to ensure the participation and inclusion of persons with disability from indigenous and diverse cultural backgrounds in its service delivery, including supporting representatives of indigenous and culturally diverse communities to participate in PWD’s Board, implementing an affirmative action policy in relation to staff from indigenous and culturally diverse backgrounds, providing information about its service in culturally sensitive ways, and ensuring that services are delivered in a culturally sensitive manner by providing staff with ongoing training in culturally competent service delivery.

4. Methodology – How this submission was written

4.1. This submission has been written by staff members of People with Disability Australia (PWD), under the direction of the Board of PWD, which is constituted entirely of people with disability.

4.2. Consultation with members of PWD took place at a Members Event, held at Redfern Town Hall on 21 May 2010, where information about the proposed National Disability Insurance Scheme was provided by a guest speaker, and questions were taken from the floor about how such a scheme should be delivered.

4.3. Following the event all editions of PWD's E-Bulletin have contained updates of PWD's progress on this, and other, submissions, and has provided opportunities for members and other readers to make contributions to the submission. PWD staff have also assisted members in developing their own submissions to the Productivity Commission.

4.4. The contents of this submission reflect the consistent view of members, expressed to staff, that a new scheme must deliver funds for supports by means of individual budgets, and that all support arrangements must be under the direct control of the person with disability, or of someone who is charged with assisting that person with disability to make the decisions necessary to manage their support.

4.5. PWD recognises that this submission represents a significant, but as yet preliminary, step in the process of determining how adequate funds are to be made available to assist people with disability in their support needs, and how those support needs are to be addressed in a new scheme. It is therefore committed to further consultation with its members, and with the disability sector, and is available directly to the Productivity Commission itself, to discuss aspects of the submission that relate to the delivery of supports in a new scheme.

4.6. This submission is also informed by a preliminary submission, made to the Productivity Commission in early August, that was intended to brief the Commissioners prior to the public hearing held in Sydney on 20 July 2010, at which one of PWD's Executive Directors spoke, and by the text from that briefing.

4.7. The submission represents one of several that have been written collaboratively with other peak groups in the disability sector in Australia. This collaboration was entered into in recognition of the need to provide detailed, evidence-based submissions, and the paucity of time available to single organisations to achieve this alone. Thus, other organisations submissions' have contributed to areas of this submission, and where this occurs they have been acknowledged. PWD also took a lead role in the development of the In Control Australia submission, and areas of that submission are also referred to, quoted and paraphrased, and acknowledged.

5. Perception of the Challenge and the Problem

5.1. The scope of this inquiry is broad, and the premise on which it has been initiated accepts that significant reform is required in the current disability service system to bring about positive change. As such, the bulk of submissions have focused on what might work, and how that might work, and not emphasised to any great extent what the particular problems are in any great detail. PWD accepts that the best use of the resources expended in this inquiry is to focus on how a new system might be funded and operated, but does contend that some aspects of why the previous system has, in general, failed to deliver upon the promise of the Disability Services Act 1986 (Commonwealth) need to be noted, so that a context is given to the proposed reforms, and also significant mistakes of the past are not repeated in the future. This section points out some significant aspects of the problems which have resulted in a disability service system in Australia that consistently fails to meet the expectations and needs of people with disability, and cannot support Australia's obligations to people with disability under the CRPD.

5.2. **Cross-jurisdictional barriers**. A significant barrier to the consistent, equitable and adequate provision of support to people with disability across Australia has been the demarcation of particular responsibilities for funding, administering and delivering disability services between the Commonwealth and the States/Territories. This has led to a plethora of inadequately funded, often pilot programs that are developed locally and not available more widely, which not only fail to address the entirety of need of individuals from a holistic perspective, but which further deny the person with disability their right to move location, as what little is provided to them cannot be guaranteed in other locations, either within or across jurisdictions. Further to this, it has been acknowledged that jurisdictional barriers exist in areas of support where, from the perspective of people with disability, a continuum of support should exist, for example in the provision of readiness to work programs, and the work and work placement programs themselves. The practice of cost shifting between jurisdictions works against proactive and positive strategies of working toward the inclusion of people with disability in the community.

5.3. **Cross-departmental/ portfolio barriers.** Although it has been known and acknowledged for decades now in Australia that disability is a form of disadvantage that impacts on people with impairments in many aspects of their lives, nonetheless the response of successive governments, at all levels, has been to focus predominantly upon the delivery of specialist services which focus in the main upon the individual impairment. Whilst these services are necessary (and indeed again the focus of scrutiny in this inquiry), there has been a failure to adequately address the barriers that continue to exclude people with disability from participation in education, in employment, in the built environment, on public transport, and in housing. One of the contributing factors has been the tendency to specialise areas such as housing, education etc into portfolios, which consider disability as belonging as a responsibility to the portfolios that specifically address specialist disability services. This continues to lead to service delivery dissonance; for example, for people with psychosocial disability, who are able to access Disability Employment Services, and be entitled to support that is subject to scrutiny under the Disability Services Standards, but for whom specialist housing and support programs are available only in some State jurisdictions, funded under Health departments, and are not subject to scrutiny under the Disability Services Standards. Such anomalies and, more importantly, denial of access to important supports to certain groups of people with disability (based on diagnosis and portfolio responsibility) need to be acknowledged and eradicated as part of the development of a new scheme.

5.4. **International obligations.** Australia is a signatory to the United Nations Convention on the Rights of Persons with Disabilities (CRPD), and as such needs to be making efforts to ensure that the provision of rights to people with disability, according to the various articles in the CRPD, is progressively implemented in all areas of Australian social life. As such all funded disability supports must be used to support outcomes which are identified as meeting the rights provisions of the CRPD, and must not, for example, be utilised to redevelop segregated, congregate care facilities. PWD makes reference to the work of the Australian Human Rights Commission (AHRC), in its submission (No. 72) to the Productivity Commission, which details how a new disability care and support scheme must be delivered so that it meets the requirement of each of the CRPD's articles. PWD, therefore, views it as essential that the Commission's commentary, and ultimately its recommendations, are formulated so as to reflect Australia's obligations under the CRPD, and certainly does not accept that models of support which violate the CRPD should form any part of the Commission's report.

5.5. **Workshop Participant Group.** PWD, together with the Australian Federation of Disability Organisations (AFDO) and the AHRC organised a two-day workshop in Sydney, with subsequent follow-up meetings, to discuss how a new disability support scheme might operate in accordance with the CRPD. The outcome of this process was a set of principles and details about how a new scheme would operate, which has broad agreement amongst those disability peaks that were present. This group will be referred to throughout this submission as the Workshop Participant Group.

5.6. **Self-directed funding.** PWD was also informed in this submission by its involvement with the group In Control Australia, which is a collaboration involving a number of individuals and agencies across Australia. Those involved share a determination to see Self-Directed Funding (also known variously as Individualised Funding, Personalised Budgets, Self-Directed Support, etc) available as a standard option for people living with disability, and also for those family members involved in their lives. Given that the Productivity Commission inquiry specifically looks at the feasibility of delivering a new care and support scheme by means of individual funding, PWD has brought together an immense amount of Australian and international knowledge about the implementation of individualised funding, primarily in the development of the In Control submission, which will be referenced throughout this submission. The PWD submission is focused, not so much on evidence that individualised funding and self-directed supports have been successfully and effectively implemented in overseas jurisdictions, as it is upon providing details about how such supports may be implemented in Australia, taking account of the issues and challenges described above. A fundamental shift that PWD advocates in the delivery of the new care and support scheme is the delivery of funds to the demand side of service delivery, i.e. directly to the individual with disability who requires support, rather than to the supply side, to the specialist disability services which provide the support to people with disability. PWD submits that a significant disincentive to deliver meaningful outcomes to people with disability exists as long as services continue to receive funding directly from government departments, without adequate accountability to the service user, and that this accountability can be most straightforwardly achieved by providing the service user with the ultimate control to purchase their supports elsewhere. PWD recognises and acknowledges that there are some excellent examples of specialist disability service provision across Australia, but that unfortunately this cannot be guaranteed until such as time as the system operates to reward quality by continuity, which can only be achieved when the service user is in control of the funding.

6. Key Principles for disability support schemes

6.1. People with disability and Disabled People's Organisations (DPOs) are to be involved in all levels of governance in a new disability service system, and to have significant decision-making power regarding the distribution of funds that are available to the new disability care and support scheme.

6.2. The CRPD is the framework for design of a new system, requiring a significant cultural paradigm shift based on a social model of disability.

6.3. The proposed scheme should be a national scheme which is:

  a. based on entitlement for all who are eligible
  b. adequately funded to meet the need of all who are eligible for it
  c. based on equity for all who are eligible
  d. based on self determination, in terms of both its operations and the outcomes it achieves for people with disability
  e. committed to the empowerment of people with disabilities, in both its delivery and its outcomes
  f. consistent nationally, and which ensures funding and entitlements are portable across all Commonwealth, State and Territory jurisdictions
  g. capable of facilitating local solutions and building supports around the individual, to the degree necessary
  h. responsive to changing circumstances of an individual
  i. respectful and trusting of people with disability to articulate their needs, and understand the supports they require to participate in the community and have the same opportunities as people without disability.

6.4. People with disability who require assistance and support have the right to be directly involved in the process of assessment, in planning how they wish to use the funds, and in the discussions where the acceptability of the plans are decided.

6.5. People with disability must have access to secondary supports that will provide, to the degree each person requires, assistance in the operation of their self-directed supports.

6.6. Safeguards for people with disability, which ensure they are supported to the degree they wish in the operation of their self-directed supports, must be provided alongside the individualised funds, in the form of secondary supports, with further safeguards provided by third-party supports which exist primarily to monitor and protect individuals from risks and exploitation.

6.7. There must be transparency in funding arrangements and appropriate consumer rights protection mechanisms.

6.8. A strong independent advocacy support program is separately funded to support and protect the rights and interests of people with disability funded under the scheme.

6.9. A robust complaints mechanism must be established to ensure that people with disability have the right to complain if purchased supports and services do not meet their obligations or achieve negotiated outcomes; and this mechanism must be at the heart of the quality assurance system that governs specialist disability services into the future.

6.10. There must be role clarity in the various functions that characterise the new system, between those who allocate and monitor funding, those who assist individuals to plan supports, and those who deliver services. The system must be structured and resourced to ensure this role clarity is enabled.

6.11. A large range of service delivery options must be available to accommodate the difference and diversity of people’s needs, and to reflect their different aspirations. Any tendency to one-size-fits-all models of service must be avoided at all costs.

6.12. All existing obligations and commitments by governments to non-discrimination and inclusion of people with disability within the broader community and delivery of human services are maintained outside this scheme – i.e. costs are not to be shifted to individuals and preventative mechanisms to prevent this happening.

6.13. This scheme will form a major initiative under the National Disability Strategy.

These principles have been derived from the deliberations of the Workshop Participant Group.

7. Productivity Commission Issues: Who should be the focus?

7.1. This section addresses the fundamental issue of who should be in receipt of the resources that are generated from a NDIS, and administered through a new Australian Disability Support Authority (ADSA). It will deal in some detail with the issue of **eligibility**, and address some of the limitations and assumptions that the terms of reference of the Productivity Commission Inquiry on disability care and support have imposed, most notably in regard to the exclusion of people who are aged 65 and over, and the terms “severe” and “profound” as the proposed descriptors of disability upon which eligibility for the scheme will be based.

7.2. This section will also briefly address the issue of assessment**,** primarily for the purpose of determining eligibility for support under the scheme, but also with a view to linking the process that determines eligibility to that which frames the need, under the same framework.

7.3. **Principles** - PWD supports the principles agreed to by the Workshop Participant Group regarding the target group for the new scheme. The Group recommendations are that a new scheme should:

- Use an ***inclusive definition*** as set out in the UN Convention on Rights of Persons with Disabilities (UNCRPD). Article 4 (c) of the UN CRPD requires that States Parties need to take into account the protection and promotion of the human rights of all persons with disabilities in all programs and policies.

- Support ***eligibility for disability support based on needs*** and shaped by the impact of a person’s impairment on their capacity to undertake normal activities of daily living. It is critical that such a scheme maintains its capacity to respond to the complexity, diversity of need and context, allow for flexibility and resist the tendency of eligibility based schemes towards rigidity of policy and application of funding principles.

- Recognize the need to include groups from the start that might fall through gaps. Including:

    - Refugees and new migrants waiting for residency and citizenship papers
    - People with disabilities in correctional services system
    - People with disabilities in segregated settings, such as institutions and boarding or rooming houses

- Include people with psychosocial disabilities (our term for what is often referred to as “mental illness”, but which is characterised more by the fact that people so designated are provided with all of their supports through the health systems across jurisdictions in Australia).

- Include people with ageing related disabilities. Specifically this refers to people who are yet to attain the age of 65, at which point they become eligible for aged care service, but who, nonetheless, are experiencing greater levels of impairment, and are in need of greater levels of support, as a result of the ageing process. PWD shares the concerns of others within the sector about the exclusion of people who are ageing with disability, and who are over the age of 65. It is understood that the focus of the inquiry is in relation to the reform of the disability sector, which currently operates apart from the aged care sector. It is anticipated that the principles of reform and self direction will also apply to the 'aged care sector', to ensure that people with disability who have attained the age of 65 are not provided with inferior options purely because they are accessing services through the aged care sector. PWD also supports the view of the Workshop Participant Group that the Productivity Commission Inquiry consider the issue of ageing with disability in the context of links between this inquiry and the separate inquiry into aged care.

- Develop an ***assessment process for individuals*** that:
    - Assesses individual's needs separately from needs of their family
    - Is based on a social model of disability,
    - Is nationally consistent with uniform standards and conducted by well trained and prepared assessors,
    - Provides an assessment at a location or setting where the individual is most comfortable.

7.4. Eligibility: There needs to be recognition that eligibility for disability support services in Australia remains one of the worst and most intractable problems that the system faces. This is characterised by:

- A lack of consistency in the definition of disability and of the criteria for eligibility for support services in each of the State, Territory and Commonwealth jurisdictions;

- The ability for government departments in each jurisdiction to arbitrarily determine whether a person has an eligible disability (for support provision), without recourse to any nationally or internationally agreed set of criteria, or which would allow appeal by those who are left without service;
- The tendency for service provision types, and support initiatives, to be determined significantly by which government department has responsibility for a set of services which it attempts to target a particular population, amongst whom are clearly people with disability, e.g. mental health services, aged care

service. This in turn leads to differential service provision and also regulation (i.e. not monitored for quality under the Disability Services Standards).

- The practice, though block-funding of services, of allowing those services to determine which people with disability get access to supports, and which don't. On the one hand this has tended to channel skills and experience in assessment to the service sector, and out of the administrative departments, and, on the other hand, has added to the lack of consistency by considering criteria that are individual service based when determining whether or not a person is eligible for support.

- The practice of centrally operated vacancy management systems to allocate resources on the basis of crisis need, which often does not take account of the person's preferences.

7.5. Eligibility for the new scheme must be based on a broad definition of disability, and must be assessed by a framework which has international validity, a robust methodology for assessing the holistic needs of a person with disability and their circumstances, and the capacity to stand as a framework for the development of self-assessment and monitoring/appeals tools. PWD believes that the definition of disability that is provided by the Disability Discrimination Act 1992 (Commonwealth) is the best and most inclusive definition of disability that underpins Australian legislation currently, and should be adopted as the benchmark for understanding what we mean by "disability". In relation to a robust and internationally valid framework for the assessment of eligibility, we recommend the ICF as the classification which can best inform tools of assessment appeals processes. The points below explain this in more detail.

7.6. A submission to the Productivity Commission Inquiry, produced by Ros Madden, Anita Bundy, Lindy Clemson, Nick Glozier, Rosemary Kayess, Gwynnyth Llewellyn, Richard Madden, Robert Manga, Elias Mpofu, and Roger Stancliffe, informs our position in points 7.7 to 7.11.

7.7. The term "severe and profound disability" is a statistical construct, which only has application to disability policy eligibility and service determination. As it only partially addresses the activity/participation domains of the ICF, and does not align with the CRPD nor with the National Disability Agreement, it has no validity as an eligibility criterion. It also does not accord with the profile of current recipients of disability support services, and is therefore likely to disqualify many people who currently do receive support.

7.8. PWD supports the recommendation that the International Classification of Functioning, Disability and Health (ICF) be adopted as the overarching framework which informs the tools that are developed to assess for eligibility for the new scheme, and also tools which match need to resources. It accepts the conceptual strength of the international classification because of its capacity to capture the multi-dimensional concepts of functioning and disability, namely:

- the **body functions and structures** of people, and impairments thereof (functioning at the level of the body);
- the **activities** of people (functioning at the level of the individual) and the activity limitations they experience;
- the **participation** or involvement of people in all areas of life, and the participation restrictions they experience (functioning of a person as a member of society); *and*
- the **environmental factors** which affect these experiences (and whether these factors are facilitators or barriers).

7.9. In addition staff at PWD were involved in the process of development of the ICF prior to its launch in 2001, and aware of the eventual collaboration that took place between the WHO and Disabled Persons International (DPI), which resulted in the classification adopting critical elements of the lived reality of disability, as expressed in the social model of disability. To this end, the then President of DPI, Rachel Hurst, declared her hope that the ICF framework will inspire policy makers to “use the environmental factors as a basis for assessing appropriate services, for underpinning non-discrimination legislation, for ensuring appropriate health care and support and that statisticians and epidemiologists will use it for their work”. To our knowledge, this would be the first occasion that Australian authorities would have lived up to the promise of adopting this framework, and would of itself be a demonstration of good faith.

7.10. This submission analyses the spread of current supports for people with disability in Australia, and concludes that there is comparatively high levels of information and relatively good targeting in relation to the three activities of self care, mobility and communication. However, these represent only three of nine categories. Current service recipients in Australia have a range of important support needs across all areas of activities and participation, and are in fact more likely to need support in areas such as interpersonal relations, learning, work and community life than in self care, mobility and communication. This indicates that there are significant limitations to the way that current supports are framed, and these limitations must not be replicated in the new scheme.

7.11. PWD supports the comments about the dichotomy between “disability” and “non-disability” being a false one, when in fact everyone in the population experiences a disability or a health condition to some extent, which can be tracked to the ICF. The scheme should, in theory, have the capacity to determine at what point assistance, no matter how small, might be deployed, so that the outcome for the individual in receipt of that assistance is one that has a positive impact on their lives. Thus, in line with this submission, eligibility could then described in terms of the frequency and amount of assistance needed in any ICF Activity/Participation domain, and the related outcomes of significance to the person; and the support provided could be shaped by (but not contingent on) the availability or willingness of an informal carer, the person's own efforts to be 'independent', and the nature of the person's environment (e.g. transport availability, housing availability). PWD cautions, however, the development and use of eligibility assessment tools which do not allow the present circumstances of support by an informal carer to be diminished in any strategy to enable the person with disability to become more independent, and achieve their goals of inclusion and participation.

7.12. This section so far has focused on the principles of eligibility to the new scheme, and the value of the ICF as a means to address eligibility in a manner which is transparent, equitable, and based on the social model of disability. Later in this submission, under the section on the distribution of funds, we offer more detailed proposals for the processes by which the level of funding to each individual should be determined.

7.13. The system currently does not cater well to people with disability from Culturally and Linguistically Diverse (CALD) backgrounds (see submission from the National Ethnic Disability Alliance (NEDA), and its contention that we should distinguish between CALD and people from Non English Speaking Backgrounds (NESB)), and PWD agrees with the recommendations in the NEDA submission regarding a stronger focus on providing support to people in these categories. The self-directed support approach does not, from evidence overseas, preclude in any way people from diverse cultural backgrounds, and so is compatible with the requirement to ensure people from these backgrounds experience entitlement to service provision to the same extent as others. We therefore accept that specific attention needs to be provided in a range of areas, including the provision of information and communication in general, as well as ensuring that the workforce is adequately equipped to be flexible and responsive in culturally appropriate ways.

7.14. The system currently does not cater well to people with disability from Aboriginal and Torres Strait Islander (ATSI) backgrounds. Identification of people with disability within ATSI communities is difficult if we persist in utilising medical diagnostic classifications as the basis for assessing need and targeting supports and services to address that need. A needs-based system, such as being proposed with the new ADSA, will be better equipped to address the need that exists within ATSI communities, because it also recognises the general environment of disadvantage in which people with disability are living. However, the new authority must implement specific measures which address the total lack of infrastructure and opportunity within ATSI communities. It must aim to achieve a culturally sensitive and appropriate, yet robust, strategy to quickly enable people in these groups to obtain the same levels of support as is available to others in Australia.

7.15. A key aspect of the new scheme is that it must be entitlement based, and universal. It must be a scheme that recognises the disadvantage that people with disability experience relative to people without disability, and must seek to include people in order to provide them with the assistance they require to be able to participate in the life of the Australian community.

7.16. All people with disability are in need of more, better and more consistent support across Australia, and the assurance of receiving support wherever they might be located. There are significant gaps in the current "system" of delivering support and service to people with disability in Australia. There are, in fact, many different systems operating at local, State/Territory and Commonwealth levels, which, amongst other things, means that people with disability, if they move between or even within States, can expect differential treatment based on where they are located.

7.17. Systems must address areas of significant unmet need, and make responses available wherever these needs may arise. Particular discrepancies in consistency and equity of service delivery where a) the system in place does not address the needs of a particular minority, such as people with disability from a culturally and linguistically diverse (CALD) or Aboriginal and/or Torres Strait Islander (ATSI) background; or b) where different systems are in operation to meet the needs of people with similar needs, but who have different diagnostic tags, eg, people with mental health problems, who in NSW can have access to the Housing and Accommodation Support Initiative (HASI), but a HASI type program is not available in most other States; and the Home and Community Care (HACC) program, is differentially targeted in different areas across the country.

7.18. Particular supports need to be provided to assist children and young people with disability, and to assist them and their families, to enable them to grow and develop to better be able to take up the choices that are available to Australian people when they achieve adulthood and move away from reliance upon their families as carers.

7.19. PWD is concerned about the potential for groups of people who are particularly vulnerable to their current living circumstances, to miss out on the new scheme, and not to gain the benefit of the support it provides. People who currently live in licensed and unlicensed boarding houses need under the new scheme to have the same standard of service provision allocated to them as to any other citizen with disability who is eligible for support. Likewise people with disability who are currently living in segregated, congregate facilities, such as institutions for people with intellectual disability, and younger people living in nursing homes, need to be provided with support that enables them to live and enjoy life in the community. PWD is also concerned about the numbers of people with disability who are in the penal systems across Australia, and looks for the new scheme to adequately fund support that will both work to prevent inappropriate incarceration, and also offer alternatives to long-term incarceration to people with disability who may offend.

8. Productivity Commission Issues: What should a new scheme cover?

8.1. Proposals for a new Australian Disability Support Authority within a reconfigured structure of social support and inclusion

8.1.1. PWD strongly supports the view that a new scheme should predominantly operate through the mechanism of individualised funding (IF). Individualised funding, by placing the control of purchasing with the individual requiring assistance, allows each person with disability to have much more choice, and more control over their lives. Each individual is free to choose services that fit into their preferred lifestyle, rather than having their life shaped to suit the availability and convenience of the services. IF calls on services providers to operate under the commercial conditions that are taken for granted in other sectors. It creates a competitive marketplace in which service organisations grow or fail according to their ability to respond to the demands of their customers. This in turn means that the range of services will be shaped by the demand of people with disabilities, largely removing the need for a state-driven service commissioning. Furthermore, IF creates the opportunity for people with disabilities – who have strong incentives to maximise the benefits from the funding – to find efficient and/or innovative solutions. These include the use of mainstream services and equipment, and support from informal community supports. Thus individualised funding tends to reduce the exclusion of persons with disability from ordinary social and commercial opportunities.

8.1.2. Individualised funding is not a panacea. In the first place, it needs to be underpinned by adequate levels of funding. International experience suggests that an IF system will use public funding more efficiently, producing better outcomes for people with disability at less cost to the taxpayer (see literature review; It would be utterly wrong to force savings by cutting overall budgets too far (or by holding budgets static in spite of rising numbers of customers). A market of providers which is starved of funds will be driven by solely by cost, with no regard for quality, and ultimately people with disability might be denied access to any services, or driven to use congregate service for reasons of economy. Clearly, these would not be acceptable consequences.

8.1.3. There is also growing evidence from international experience that the potential benefits of IF will not be realised unless it is set within a structure that is well designed and strong enough to resist reactionary, counter-progressive influences. In particular:

- **Centrally defined design**

  The critical elements of design of the system, and major operational policies (e.g. acceptable uses of funds), must be defined. There are two reasons: Firstly, it is important in order to ensure equity of access and levels of funding from locality to locality, and across States and Territories. Secondly, a sound management plan needs to be in place to support individualised approaches and to enable self determination by people with disability.

A central system with overarching responsibility is required. However, there needs to be flexibility to build on the strengths of local responses and initiatives. This is a fundamental strength that needs to be in place.

- **Empowered and informed choice**

  People who receive individualised funding must have ready access to the information and support they need in order to take control of purchasing decisions. People do not become empowered simply by knowing the cost of their support services. They need to be aware that they can make different choices, have the information to make the choices that suit them best, and be able to put those choices into action. Although some persons with disability will be able to take on these tasks, many others will need or prefer to have some assistance.

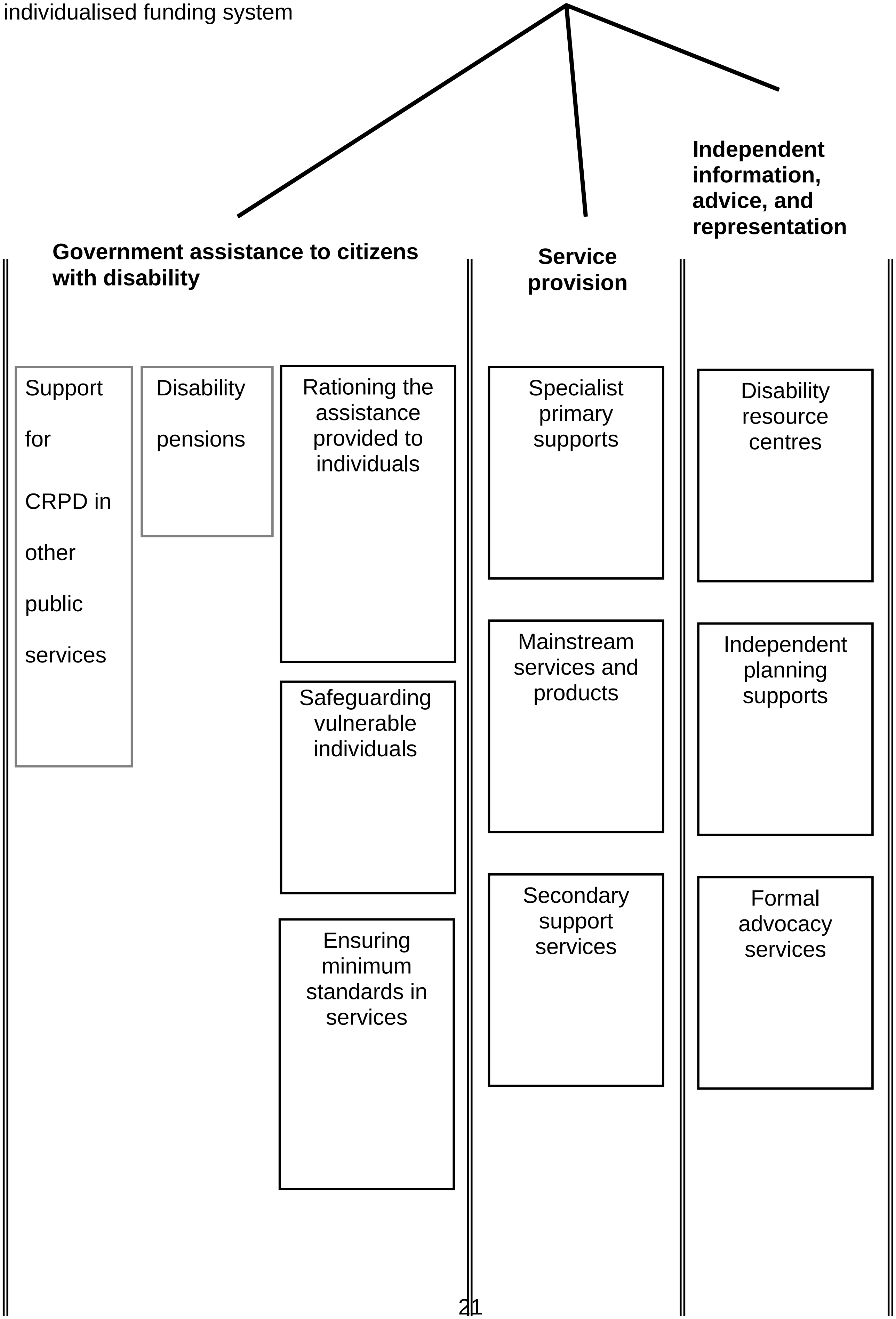
- **Independent, customer-focused planning support**

  Assistance with planning and organising the use of individualised funding can come from many sources, and people should be free to choose the source they prefer. *However, people should have the option to use a service which provides specialist assistance, and which offers the assurance of a minimum level of knowledge and skills, and independence from government and service providers.* The availability of this type of support – often known as independent brokerage - is particularly important during the process of transition from a system in which advice and guidance has been subject to major conflict of interest, and therefore not perceived to be trustworthy (See the In Control submission – Literature Review on “brokerage”).

- **Structurally separate advocacy and planning support services**

  The structure of the system must provide a location for these independent services, separate from government and service provision, with systems of funding and regulation designed to protect their independence. With the addition of independent planning support as a key element of a system based on individualised funding, it becomes vital to reconfigure the social care system into a tripartite structure, with advocacy, brokerage, and other independent, consumer-centred services on a separate arm. (See diagram on page below.) Additional measures are required to ensure that the independence of these services is not compromised, for example by terms of reference that constrain accountability to government, and regulatory systems that are controlled by citizens with disability and their chosen allies.

Major elements of a tripartite individualised funding system



8.1.4. Assessment of risk – individual arrangements

We have proposed that the final decision on release of funding should, by default, be through a process of face-to-face negotiation. In practice this may not always be necessary. The individual's plans for the use of the money may be so straightforward that there is no need for a meeting. This is particularly likely, of course, when the amount of funding is small.

On the other hand, other plans may be costly and elaborate, and raise issues that need to be discussed. In particular, they may present risks, perhaps involving breakdown in support arrangements, inadequate levels of support, exposure to dangerous situations, or misuse of funds. These are all issues that need to be discussed and agreed.

Although it is unlikely, it is possible that the Support Plan will create risks that are not identified in the Plan, with the consequence that the Plan is agreed, and funding released, leading to serious problems later on. For this reason it is very important that the system includes a route through which the funding agency can obtain information about the individual in addition to the information included by the individual in their Support Plan. The structure we have proposed leaves State human services with the responsibility to gather and provide this information. It is very important that this duty is not given to independent planning support services, as it would pervert the role of these services, making them agents of the fund-distributing agency.

8.1.5 In addition there are some policies that have a critical impact on the success of individualised funding as a mechanism to use public funds effectively, improve outcomes for persons with disabilities, and uphold their rights and social inclusion. These include the following:

- **Release of individualised funding through directly negotiated agreement**

  Although assessment should be used to identify the approximate level of funding available, the mechanism for agreeing the actual amount, and permitted uses, should be based on the principle of a negotiated balance between the individual's requirements and the available funding. In practice this negotiation may be unnecessary, especially where the amount of funding is small. However, a negotiated settlement should be the default which can be waived, rather than making it the exception where a complaints procedure has been invoked.

- **Flexible use of funds to meet legitimate needs**

  The rules for the use of funds must be loose enough to allow individuals to meet legitimate support needs in innovative ways, and not only through the use of specialist support services or personal assistance. For example, purchase of domestic equipment might partially replace the need for support, and be a better, more cost-effective solution.

- **Purchase of secondary supports**

  The level of funding allocations, and the policy of acceptable uses, must be sufficient to enable individuals to purchase ‘secondary supports’ such as payroll and accountancy services, or support coordination, to underpin the primary supports they choose. Many people will not want to take on these responsibilities, or will not have the ability to carry them out. Thus, for many people, these secondary supports will represent an essential part of the package of supports and resources obtained with their individualised funding.

- **Regulated fiscal intermediary options**

  Arrangements where the allocated funds are not passed to the individual must be regulated to ensure they do not reduce the level of control by the individual. Although the most certain way to pass control over the funding is an arrangement whereby the individualised funding is passed to the individual, arrangements which involve the use of a third party – a financial intermediary - to hold the funds and make payments on the individual’s instructions, can still leave the individual in control while avoiding the administrative burden. Such arrangements can also be useful where the fund allocating body needs reassurance that the money will be used for agreed purchases. There is, nevertheless, a risk that these arrangements will undermine the person’s control. This is particularly likely to occur if the financial intermediary has connections to government or to service providers. For these reasons, the acceptable types of financial intermediary arrangement should be defined centrally, and individual financial intermediary agents should be subject to regulation.

8.2 Applying these design principles to the development of a new national system

The creation of a new national service has to take account of the services for children and adults with disability that are currently being provided by the States and Territories. This is a difficult issue, of course, in view of the variations in the form and adequacy of those services. It might seem best to sweep all these services away so that the new national service can be built ‘on clear ground’.

However, we believe that this would be a mistake, for the following reasons:

8.2.1. In reality, the prospect of clearing away the old and starting from scratch is an illusion. The new service will need to re-deploy the professional workforce currently operated by the states and territories, and will need move to interface with the range of providers that exists at present. Whereas it may be attractive to start with a clean break from a broken system, the people who have relied on that system need to be helped with support and assistance through the transition.

8.2.2. Completely dismantling the old state systems would mean throwing away some programs that are very good, and deserve to be retained.

8.2.3. Leaving some responsibilities with the states and territories provides extra opportunities to divide roles and responsibilities in ways that reduce conflicts of interests, and play to the strengths of each.

8.2.4. In particular, States and Territories should be best placed to work with their own communities in ways that will benefit their citizens with disability. These activities include linking to other public services, such as education, to forecast and monitor the demand for services by citizens with disability. In some situations this may point to future service requirements that will not be answered through the mechanism of individual funding, so States and Territories may need to commission services or stimulate market development. States and Territories should also work to ensure that the activities and opportunities within ordinary community life are fully available to citizens with disabilities.

8.2.5. Lastly, we would have to add a concern that a single national organisation with responsibility for all aspects of social care, other than service delivery itself, could become remote and bureaucratic. In order to counter this there needs to be a real, visible presence on the ground in local areas, where the applications of funding decisions can be made and rendered accountable. This would further entail excellent coordination and cooperation between States/Territories and the Commonwealth. This might be achieved by encouraging a uniform Office of Disability at the Commonwealth level, and in each of the States and Territories, which have carriage of the overall interests of people with disability in each jurisdiction in line with our obligations under CRPD.

8.3 Roles and responsibilities in a new support system

The arguments set out above lead to a new tripartite system, with major responsibilities designated as follows:

A Duties undertaken by the new Australian Disability Support Authority

We envisage that the new authority would provide overall direction from the centre, while establishing State and local offices which would undertake the processes required to allocate funding to individuals. As a whole, the duties of the new service would be as follows:

A1 Set standards to be followed across States and Territories for:

- Criteria for access to funding through the service.
- Relationship between level of funding and needs arising from disability (e.g. as generated through the assessment process).
- Criteria for approval of individual plans, including permissible uses.

A2 Allocate budgets to State, Territory and local offices for distribution as individual funding allocations.

A3 Allocate funding to an organisation, under control of persons with disabilities and families, in each State and Territory that will oversee the provision of independent advocacy, planning support, and financial intermediary services (See section C, below).

A4 Monitor use of funding for individual allocations at local state and national levels; collate information on outcomes and unmet need, and report to national government.

At the local level:

A5 Ensure that persons with disability and their families can access information about the service, and the procedures to be followed to be awarded funding.

A6 Implement a system of assessment, based on national standards, to identify appropriate levels of funding to individuals.

A7 Provide a system for the approval of support plans and the release of funds to individuals, ensuring that individuals are able to present their plans and negotiate directly with decision-making officers of the authority.

A8 Ensure that this system for the approval of plans includes a mechanism through which information from state human service professionals is gathered to assess risks presented by the plan.

A9 Review outcomes from implementation of each person's plan.

B Duties retained by the States and Territories

As discussed earlier, we believe that the States and Territories should retain some responsibilities. Specifically:

B1 Fund and deliver general guidance, therapeutic and safeguarding professional services, e.g. social work assisting persons with disability and families.

B2 As part of these services, provide input to the process by which local ADSA officers assess the acceptability of Support Plans, particularly with reference to risks posed by plans.

B3 Monitor and forecast the pattern of demand for services, in terms of geography, type of disability, the needs arising from disability, and from barriers that preclude access to general community activities and services.

B4 Commission social care services to ensure that there is capacity to meet current and emerging need amongst persons with disability for these services. (Supply-side activity of this sort will be supplanted by the emergence of a demand-led market driven by the holders of individualised funding. However, action to ensure capacity to meet needs will be required during the transition process, and also where the type of support is specialised and/or required in remote areas).

B5 Inspect specialist support providers to ensure that minimum standards are met, with associated capacity to respond to complaints.

B6 Ensure that the commissioning and operation of all public services by the State/Territory are designed to deliver services that are consistent with the CRPD and which facilitate the social inclusion of citizens with disability.

B7 Monitor the community opportunities available to persons with disability, and take action as appropriate to ensure that gaps in the range of opportunities are filled, and that community resources are both competent and welcoming in their response to persons with disability.

It has to be recognised that these represent essential duties within the new system, and some States/Territories would need to carry them out more fully and skilfully than at present. As discussed in the section of this submission which describes the process by which funding would be allocated to individuals, State/Territory human services would have a particularly important part to play in supplying information to assist the new service in assessing risks associated with the release of funds to individuals. It may be best, therefore, to incorporate these responsibilities under each State/Territory Office of Disability.

C Responsibilities and services undertaken by the independent arm

This major element of the system separates the function of rationing from services that should be entirely person-centred, thus removing the fundamental conflict that has been present in services to person with disability. Funding for this third arm would need to be provided through the new national service, but in a way that does not undermine its independence. This is best achieved by funding that is:

- routed from the centre, not through State/Territory offices
- routed to organisations that can demonstrate that they are under the control of persons with disability, carers, and their chosen allies
- offered on terms that require limited accountability to the new service.

The role of the organisations established in this way would be as follows:

C1 Commission and regulate local advocacy services.

C2 Commission local information services for persons with disability, e.g. pensions, equipment, one-off help with support planning.

C3 Promote and regulate the development of independent planning support (“brokerage”) services.

C4 Act as intermediary between persons with disability and the new service where the level of brokerage service provided to the individual appears inadequate. (This assumes that a mechanism would be established where individuals are automatically enabled to access broker services of their choice, at a level based on their funding allocation).

C5 Regulate specialist organisations offering secondary supports, in particular agencies holding funding allocations on behalf of individuals.

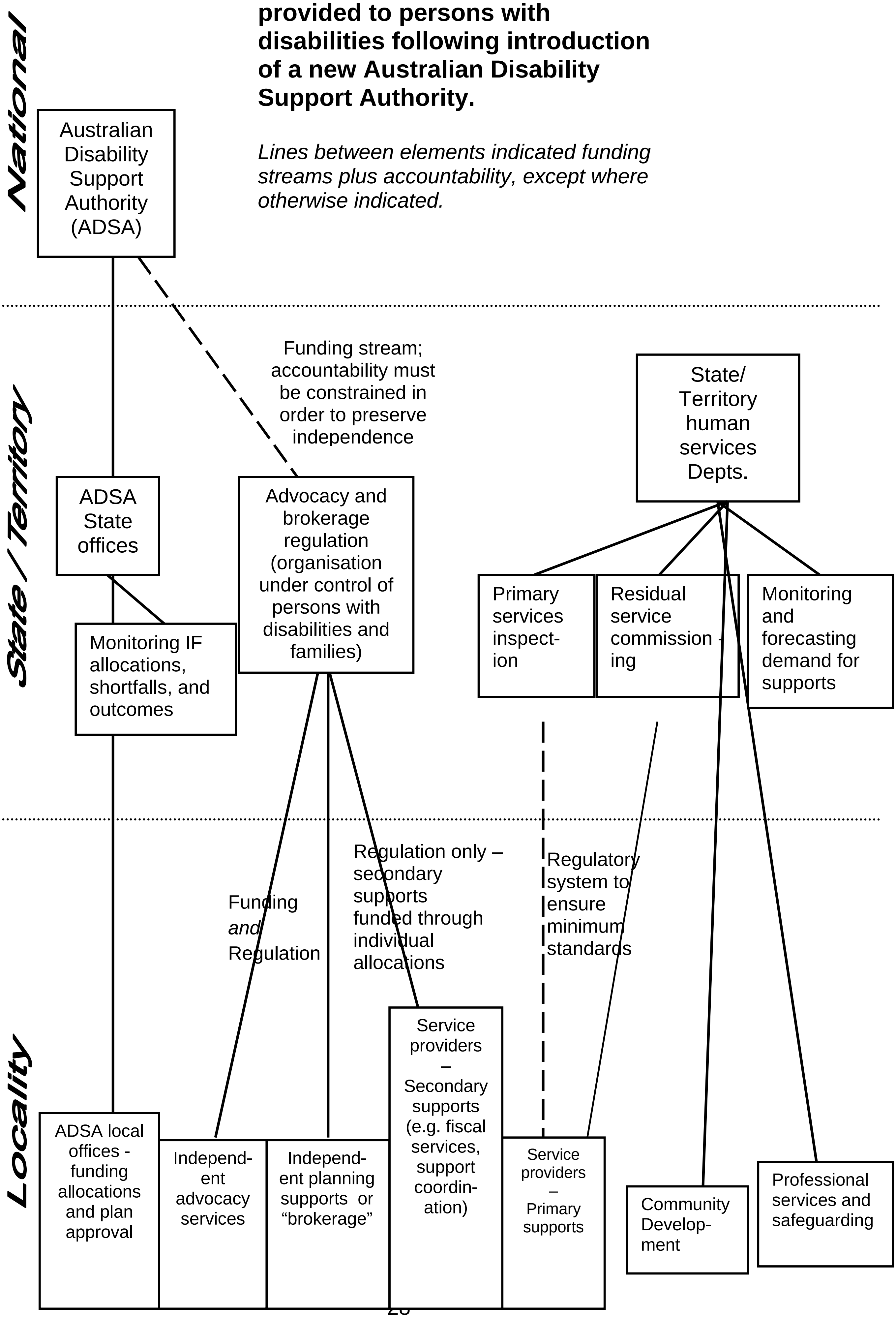
C6 Act on behalf of persons with disabilities and families to make representations to local, state, and new national service levels on the operation of the new service. For example in the level of funding, criteria for approval of plans, and the operation of the local systems to approve plans submitted by individuals.

C7 The distinction between advocacy and brokerage will have to be clear, and it is likely that agencies will not be able to carry out both, given the important safeguarding role that independent advocacy will continue to play, ideally to a greater extent than is current, in the new system.

These responsibilities are summarised in the diagram on the following page:

Major components of services provided to persons with disabilities following introduction of a new Australian Disability Support Authority.

Lines between elements indicated funding streams plus accountability, except where otherwise indicated.



8.6 Types of services and supports

8.4.1. The new system needs to be focused on the delivery of supports, rather than the provision of services. This means a fundamental shift in the way that service provider organisations conceptualise the delivery of supports, to being flexible in the delivery of what is required to actually achieve outcomes for individuals. Many of the aspects of support provision that are currently delivered will continue, but the focus will be on achieving for the individual directly, not to the broad constituency of service user, with the hope that some good may come from the support that is provided. Targeted, professional and responsive services will need to be provided to ensure a significant paradigm shift in the supports that people with disability receive.

8.4.2. The past twenty four years, since the passing of the Commonwealth Disability Services Act 1986, have been spent trying to replace the totality of the institutional model with a patchwork of specialist services that cater to a particular aspect of a person with disability’s life, e.g. accommodation, day placement, employment, recreation, respite, behavioural support etc. The skills that practitioners have gained from applying these discrete services must be retained, enhanced and transferred to the delivery of individualised support responses that will need to draw on many skills from the one staff member/provider.

8.4.3. Funding for individualised disability support needs to support full participation in all areas of life – political, civil, social, cultural & economic – as set out in the various articles of the UN Convention on Rights of Persons with Disabilities. A definition of disability support needs to:

- be broad to take into account the diversity of support needs according to the individual context – cultural diversity, geographic remoteness,
- allow for changing needs due to changing circumstances across the lifespan
- have a capacity to respond to a crisis situation

8.4.4. A new scheme should provide support based on self-determination of need. This approach needs to make allowance for supported decision making for people who require assistance and also needs to recognise the specific circumstances of those who are impacted by restrictive practices or who are in custodial settings such as prisons, detention centres and institutions.

8.5. Discussion regarding risks of new scheme

8.5.1. PWD accepts that an assessment of risk needs to be undertaken prior to embarking upon a new way of delivering supports to people with disability. However, support to people with disability has been implemented using individualised funding since the 1970s, and the outcomes of individualised funding arrangements have been evaluated positively. A well established scheme should acknowledge and address genuine risks, and also strongly repudiate the perception of risk, where none in fact resides. The section below identifies real and perceived risks.

8.5.2. Real risks

Funding will be inadequate: If the personal budget is insufficient then clearly the self-directed method of funding distribution will not succeed for the person with disability. However, the same goes for unmet and under-met need within the existing service system; a situation which gave rise to the development of this new approach to address the support needs of people with disability.

Rip-offs: There are a small number of rip-offs in every system. Overseas experience shows that this is not a major problem and does not characterize the system of self-directed support funding. A series of checks and balances will ameliorate any emerging problems at an early stage.

Impacts on the industry: Self-directed support funding will certainly offer real opportunity to flexible and responsive service providers, but will require significant change within existing services. Within an environment of disability population growth, it is anticipated that the industry will evolve over time and possibly coordinate and integrate more productively with generic services.

OHS & conditions etc for workers: Self-directed support funding is likely to extend the sources of workers available for support services. When a friend or family member is employed under a person's self-directed budget, that employee will be subject to the same or similar protections and responsibilities as provider-based employees engaged in support services. Again checks and monitoring will ensure a fair system.

Contracting, guidelines, data collection structures that properly enable self-directed funding: At present, government funding and contractual obligations do not easily enable the implementation of self-directed support funding. While people with disability and their families prepare for a new and improved supports and industry anticipates change, the government must also create administrative pathways that facilitate the implementation and expansion of self-directed funding. This will involve new and responsive contracting arrangements, flexible and non-prohibitive guidelines, data collection that both defines outcomes and creates appropriate measurements, reporting systems that are easily managed and do not diminish the value of either the personal budgets or the outcomes achieved, quality monitoring that supports individual choice. Pilots or trials can be conducted under exclusive contracts, separate from the usual obligations but the deliberate and extensive implementation of self-directed supports must be properly and easily enabled by new and flexible government administrative systems.

Data collection: It is extremely important that an evidence base is produced from the start of this new responsive system. The type amount and quality of data collected about personal budgets will provide evidence of progress and success of the self-directed funding system. This evidence base will provide a critical resource for the ongoing development and roll-out of self-directed support funding. Accordingly, government must work with the disability sector to develop appropriate data targets, definitions and collection systems.

Adequate supports in remote areas: The needs of people with disability living in remote areas of Australia are exacerbated by the lack of infrastructure (often), and the lack of suitably trained staff to provide the required support (frequently). The flexibility inherent to the individualised packages, and the way in which funds are spent, allow for local innovation in terms of purchasing the required support, perhaps not from a specialist disability service provider, but from local people who can be provided with specialist training to undertake the support required. Individually funded arrangements from around the world (in particular direct funded arrangements where people with disability employ their assistants directly) are characterised by the resourcing of local people, who may not have previous disability service experience, and who are trained up specifically in how to assist that individual. Opportunities will also arise from a better funded system, so that service providers, who are able to respond to user requirements, may be better able to establish themselves where currently lack of resources do not allow.

8.5.3. Perceived risks

Jobs will be lost: Given the increase in the number of people with disability both in real terms and possibly as a proportion of the population, the provision of supports to people with disability is likely to be growing for many years to come. The nature of some of the jobs in the disability industry is likely to change, as is the industry itself over time, but within such an environment of growth there will be no loss if jobs.

Not enough workers: This environment of growth in disability supports is currently putting pressure on the availability of the workforce. Competing sectors and relative wages and conditions are all factors in the difficulty of attracting and recruiting workers to provide disability supports. This is the situation now in the existing system. While self-directed support funding can engage the personal connections and resources of the person with disability and their family/community, the shortage of available workers is a continuing problem. However, given that this is an issue regardless of the funding distribution method, it is important to people with disability to improve the supports they require to live an ordinary or a good life. The strategies that are needed to address workforce shortages can be implemented simultaneously to the extension of self-directed supports, thereby addressing workforce within an environment of positive change for people with disability rather than simply remaining static.

Workers will be poached: It is true that service providers often complain that they recruit new workers, provide training and qualifications and then the workers leave to greener pastures. Under self-directed support funding, this is likely to continue. However, as this is an existing issue it can be seen as part of the value-adding of specialist disability service providers in addition to the actual supports provided to clients. Self-directed support funding is likely to neither resolve nor exacerbate this issue.

Impact on industry: There will be a continuing need for the specialist disability support industry. People and families will require specialist supports from these providers. A vibrant and responsive disability provider industry will be one of the essential elements of the success of self-directed supports to people with disability.

Funding as a trading commodity: Self-directed support funding is not a voucher system and should not be considered in this light. One of the pitfalls of voucher systems for social supports is that in themselves they can become pseudo-money or trading commodities, with an inherent value, that could provide perverse outcomes for consumers. Only when people with disability are empowered to become actual purchasers can they really and equally participate and contribute within the community and society in general.

Disagreement between person with disability and primary carer/family: Within the existing service system, disagreement between the person with disability and their carers can impact on both the nature and outcomes of services provided. The primacy of the person with disability must be recognised and respected, while the inclusion of carers is a critically important feature of successful outcomes. This will remain the case under self-directed support funding, recognising that a funding distribution method can positively or negatively affect the relationship but is not directly responsible for managing it.

Quality & philosophical integrity could be diminished: Checks and balances will be in-built features of a successful, positive, strengths based and progressive funding distribution system like self-directed support funding. Information and advocacy are also critical features that will safeguard against unwittingly repeating even well-intentioned mistakes of the past. People with be informed and encouraged to consider positive outcomes for people with disability as the first principle for support planning and this will often involve professional advise/expertise and advocacy. Quality monitoring will also be an additional systemic protection.

8.6 Safeguards

8.6.1. The primary safeguard is the strength of the process of individualised funding and self-directed support, which, if implemented with adequate supports, significantly benefits the service user, and also provides direct accountability for dollars spent on meeting that person’s needs. The delivery of support in the community, as opposed to in segregated and hidden environments, provides another level of preventative safeguards. The focus that exists in good self-directed arrangements, upon ensuring that the person using the service is at the centre of decisions about the supports, and about their life, is also a positive, proactive safeguard.

8.6.2. The second level of safeguards comes with the guarantee to fund secondary supports, which can assist people with disability to manage their budgets and the support arrangements that provide them with assistance. Whilst the new system must adopt a more mature relationship of trust between the authority and the person receiving the funds and support, the ability to utilise assistance with whatever aspect of the support arrangement must be available.

8.6.3. Safeguards must be provided by well-resourced, skilled, independent advocacy. This submission has proposed that funding for a nationally resourced, truly independent advocacy program, which has a governance structure of people with disability, come from the NDIS, or whichever scheme is chosen to raise the funds for the authority.

8.6.4. A robust complaints and investigation department must also be established, to look into breaches of any aspect of the funding and support agreements, and also to consider appeals from people with disability who claim not to have been treated equitably by the system. If the new authority is governed, as we suggest, by people with disability, and families and carers of people with disability, then this department can operate within the authority. If the new scheme is to be administered by a government department, then the complaints and investigation function needs to be undertaken by an independent agency.

8.7 Resourcing the Sector

8.7.1. A new scheme will need to invest in initiatives that build community capacity, provide good information, encourage empowerment and choice and promote innovative development of disability support strategies that are life enhancing and value adding for people using individual budgets. In areas where “the market” has failed, specific development of supports may be necessary. The development of regional/local disability resource centres managed and operated by people with disability and their organisations is suggested as a possible structure for doing this work. These disability resource centres might also play a role in stimulating and supporting informal supports of families, friends and neighbours within local communities.

8.7.2. The continued development and improvement of service infrastructure will need to continue, with less emphasis on forcing competition based on cost (for general disability support), and more upon the filling of skills and service gaps in particular locations.

8.7.3. An individually funded system will drive innovation at the individual support level, which in turn will drive the growth of skills in being responsive and flexible in meeting individual needs.

8.7.4. The distribution of specialist skills, such as those utilised by therapists and allied health professionals, has never been well coordinated, and should fall to the responsibility of each State and Territory to ensure that all areas where people with disability may be part of the population, have access to the required professionals and their expertise when required.

9. Productivity Commission Issues: How much funding? Who decides this?

9.1. The amount of funding that is provided to the new scheme must be determined by the demand for resources, which emanates from people with disability who require these supports to be able to participate in the same way as others in our society.

9.2. PWD believes that a separate source of funding, that is dedicated to resourcing support to people with disability, in an open and explicit way, needs to be initiated. Furthermore, the amount to be raised for funding needs to be adequate to apply with equity to all people with disability who require assistance. PWD does not have the resources at this stage to commission any financial or economic modelling to determine how much money is required to meet current need, and growing future demand, and believe this needs to be a focus that the Productivity Commission can bring to the Inquiry, once the submissions on how a new scheme should operate, have been collated and analysed. For the time being we are happy to endorse the proposals put forward by the Workshop Participant Group which discussed the Issues paper in its entirety at the Sydney meetings on 12 and 13 August:

- A ***National Disability Social Insurance Scheme*** funded by an insurance levy (like Medicare) to fund all legitimate claims for disability support. While the capacity to provide an entitlement based scheme is attractive when compared with current situation, there are also concerns about how the insurance culture might continue to paint disability as something negative to be insured against. Other concerns are how an insurance driven scheme might use cost driven thinking to impose support strategies that would undermine self-determination and choice for individuals. E.g. Might some deaf people be pressured to have Cochlear Ear Implants to save on interpreter costs? If this scheme is to closely linked with Medicare, there is a risk that it might reinforce a medical model of disability – as against supporting a social model approach set out under the UN Convention on Rights of Persons with Disabilities.
- A new ***dedicated or specific purpose tax*** to be introduced to promote universal access to disability support funding. The purpose of such a tax would be to support an individual to fully participate in all areas of community life and to optimise their contribution to Australian society. It was suggested that funding allocated for this scheme could be benchmarked against the percentage of national Gross Domestic Product (GDP) committed to this program. This would create a basis for measuring government performance and assist us to track progressive or regressive trends in expenditure.
- ***Private contribution*** is also suggested by the Productivity Commission Inquiry paper. The working group did not support the idea of an asset test for full entitlement to the scheme.

- The working group felt that ***further research*** is needed to develop a better understanding about both the market place economics and different models of insurance that could be considered to support such a scheme.

9.3. Individualised funding systems as a necessary supplement to entitlement-based pensions

9.3.1. PWD recognises that there are a number of advocates for a pension-based scheme, which would have the capacity to deliver the resources necessary to assist an individual with disability to access the supports (s)he requires, by way of additional benefits to the base-rate of pension. However, we recognise that such an ideal remains a long-way off, and in the interim, significant reform must take place in the way that resources are allocated to deal with the impairment and disability related needs of individuals. An enhanced pension and benefit scheme, in an ideal world, may one day take account of this. In the interim, PWD believes that reform does need to take place within the system of pensions and benefits, so that some costs that are clearly associated with disability, such as pharmaceuticals, additional housing costs, mobility costs etc, are adequately recompensed. Pensions and benefits such as these should remain entitlements, which preserve the rights, freedom, and privacy of persons with disability. PWD views the new scheme as being the system that can provide higher levels of assistance, set at amounts that reflect each person's requirements, and make efficient use of available funds, in return for some justifiable moderation of the principle of entitlement. This, in essence, is the rationale for individualised funding. The delivery of a new scheme under individualised funding mechanisms draws together the social security benefits and the specialist support entitlements which will address more completely the barriers that currently impede people with disability.

9.3.2. The structure of roles and relationships in an effective individually funded system has been set out earlier in this submission. In this section we suggest a set of policies and procedures to allocate funds to individuals. These combine the strengths of a number of individually funded systems in England, Canada, and the USA.

9.3.3. We suggest that access to assistance from the scheme should be determined through three levels and stages:

- **Firstly**, a gatekeeping process, to determine:
    - o whether the need for assistance arises from disability; and
    - o whether the need for assistance, taking due account (see below) of the unpaid assistance available is high enough to warrant the provision of funding.
- **Secondly**, assessment to determine the approximate level of appropriate funding, focusing on the need for additional support to compensate for the

effects of disability. This would also need to take into account the amount of informal assistance that the person can expect to receive. A number of assessment procedures have been developed that provide a transparent and fairly equitable process by which to identify an approximate or guideline level of appropriate funding.

- **Thirdly**, agreement, through a process that defaults to negotiation between the Authority and the individual, and/or individual's representative, on the actual amount to be allocated, based on the plans for the use of the funds set out in writing by the individual. This would make it possible for the amount of funding to reflect factors specific to the individual and their circumstances, rather than the limited range of functional issues picked up in the assessment at the second stage. Differences between the guideline amount and the actual amount would nevertheless have to be justified.

9.3.4. This process, while still retaining some elements of a system based on entitlement, ultimately leads to a contractual relationship between the individual (or family/representatives on their behalf) and the national service. A system based on contracts of this sort has the potential to establish a relationship between citizens with disabilities and government human services that is typified by trust rather than – as is too often the case at the moment – hostility and mutual suspicion. However, this will not occur unless there is clear and sustained adherence to the principles of transparency and role clarity. The scheme would also need to demonstrate that it is ready to respond to changes in the support needs of individuals.

9.4. Unpaid support from family members

9.4.1. The assessment instrument that is used to identify guideline funding for an individual can be designed to disregard, or take account of, the support being provided by family members or other people on an unpaid basis. In other words, it can assess the 'gross' support need – for example the assistance a person needs to get up and dress in the morning – or the 'net' support need remaining when unpaid help is taken into account. This is not a technical issue, but a major policy question, and one that highlights our society's attitudes to persons with disabilities and the expectations placed on carers.

9.4.2. If funding is calculated on 'net' support needs, it will trap people in their existing arrangements. The adult with disabilities who is living with their parents, and dependent on them for support, will be denied the level of funding they require to establish a home of their own. Equally, the parents will face the prospect of continuing provide support until it is halted by death or infirmity. Meanwhile, an individual who was already living independently when they acquired a disability will receive a higher level of funding that may enable them to retain their own home.

9.4.3. When the person with a disability is a young child, it is reasonable to expect the parents to provide most of the support, and to calculate funding on the basis of net support needs. As the child grows up, the support they need in comparison with non-disabled children of the same age will increase, and this should be reflected in the funding offered (which might, for example, be used to pay for respite care). A just system would recognise that once the person is an adult the natural obligations of the parents rapidly decline, and would disregard the input of parents in calculating the guideline amount.

9.4.4. We recognise, however, that Australian society has long presumed upon the families of adults with disabilities to be the primary carers, relying on them to deliver support services worth many millions of dollars. A new system that decided to meet these costs would suddenly acquire an extra financial burden that would be very difficult to meet. Nevertheless, we strongly believe that there should be a commitment built into the new system from the outset to reduce the reliance upon family members for unpaid support to adults with disability. This can be reflected in the method of calculating the guideline funding which includes a formula for discounting carer support in a way that decreases with the person's age.

9.5. The Support Plan

9.5.1. The proposed individualised funding system relies on a document that sets out the way in which the individual intends to use the funding provided by the new scheme. This document is known in some individually funded systems as a Support Plan1. The plan should be based on the individual's aspirations and preferences, and in that sense is person-centred. On the other hand it serves as evidence to the agency responsible for distributing funds as evidence that the money will be used appropriately, and forms the basis of the contract between the individual and the agency. Thus it can also be seen as 'system-centred'. These competing requirements need to be balanced carefully in the rules governing the way in which it must be written.

9.5.2. In order to meet the requirements of equity and transparency, the acceptability of a Support Plan must be judged by explicit criteria. These should not unduly limit the individual's choice, for example by requiring funding to be spent on specialised support services or expecting the person to subscribe to a lifestyle which is not of their choosing. (For example, it is certainly to be hoped that improved funding and services will lead to the greater social inclusion of citizens with disability. However, it would not be right to impose greater social inclusion as a condition of funding release.)

Suitable criteria have been developed and tested in other jurisdictions, for example the seven criteria developed by In Control in England (reproduced on the following page)

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[1] This Support Plan document, which describes the overall plan for the use of funding, and which may involve a number of support agencies, plus other costs, is not to be confused with a Support Plan that specifies the service to be delivered by a single agency.

Question	**What this means**	**What care managers will look for**	**Your plan will not be agreed if…**
1. What is important to you?	If someone reads the plan, they should get a good sense of your lifestyle. They should get an understanding of who you are, and your interests and hopes for the future.	Information about you. For example: what is important to you, any experiences that may feel relevant, people who are important in your life.	Your plan will not be agreed if the information in the plan treats you like a stereotype, and does not express your individuality. Your plan will not be agreed if it is written in very general terms. .
2. What do you want to change?	The plan should say what you want to change about your lifestyle. This may include changing where you live, changing services that you receive, or changing how you spend your time.	Changes must be realistic and achievable. The changes can include long-term changes that you would like to make. These must then be broken down into achievable steps.	The plan will not be agreed if it does not clearly specify what you want to change or if the changes appear to be imposed by others. The plan cannot be agreed if the actions would make your situation worse.
3. How will you be supported?	The plan should say what kind of help or support you are going to use to make the changes you want in your life. It should say how you will make sure you stay safe and well.	The plan should say exactly what support you want, when you need it and how you want this to be provided. It should say who will provide this support or help - for example, from family or friends, or paid assistants. It should include information about how you will manage any risks, and what support you need to stay safe and well.	The plan will not be agreed if you have no idea how you are going to use your Individual Budget to get support. The plan must not be agreed if you or others are at great risk of harm but you've done nothing about it. There is guidance on health and safety on the in Control website: www.in-control.org.uk.
4. How will you spend your Individual Budget?	The plan must set out how you want your Individual Budget to be used.	The plan should say how you will use your money. You can have your Individual Budget as a direct payment,	The plan will not be agreed if the plan does not say how your money will be used. If you are taking your Individual Budget as a

	If you want to use your money as a direct payment, or an indirect payment, then the plan needs to say what your support service will cost for a year, and what money will be needed for the following two years.	or it can go as an indirect payment to someone you trust. Indirect payments can be made to an agent on your behalf or to a few people who form themselves into a Trust. You can also ask your care manager to buy a service on your behalf – a service that provides the support set out in your plan. Another option is to have your money as an Individual Service Fund with a support provider. This means that they agree to work to your support plan and only to spend your money on you. Remember that there are lots of kinds of support you can spend your money on. You aren't limited to paying for support from personal assistants.	direct or indirect payment, then the plan must say how much the service will cost. The plan will not be agreed if the service costs more than the amount that has been agreed. The plan will not be agreed if you are going to do anything illegal!
5. How will your support be managed?	The plan must explain how any support you pay for is going to be organised.	The plan should say who is going to manage the money. If you are going to employ people, it must say how you will sort out the payment of salaries, how people will be supported, trained and supervised, and other arrangements.	The plan will not be agreed if it is unclear who is responsible for what, or if you don't intend to do everything that you must be do by law. The plan must take into account employment and discrimination laws.
6. How will you stay in control of your life?	The plan must say how you will stay in control of your own life. This means thinking	The plan should describe the decisions that you will be making, and those that others make.	The plan will not be agreed if it looks like others are making decisions for you if you could reasonably make those decisions yourself.

	about what decisions you will make. Where other people make decisions for you, it has to be clear how they involve you and get your agreement.	If someone else is going to manage your money on your behalf (for example an agent, Trust, care manager, or provider), the plan should say how you want to review your support with them.	
7. What are you going to do to make this plan happen (action plan)?	The plan should set out real and measurable things that will happen in the future. In that way it is possible to look back and see whether the plan is working or not.	The plan should say who will be responsible for each action and when it will be done. The plan should say how you will check your action plan to ensure that problems can be dealt with as they arise. It should be clear how these actions will help you to make the changes that you said you wanted to make.	The plan should not be agreed if you just said some general things that need to happen. There need to be clear actions that will make sure your plan will happen.

9.6. Assessment of risk – individual arrangements

9.6.1. We have proposed that the final decision on release of funding should, by default, be through a process of face-to-face negotiation. In practice this may not always be necessary. The individual’s plans for the use of the money may be so straightforward that there is no need for a meeting. This is particularly likely, of course, when the amount of funding is small.

9.6.2. On the other hand, other plans may be costly and elaborate, and raise issues that need to be discussed. In particular, they may present risks, perhaps involving breakdown in support arrangements, inadequate levels of support, exposure to dangerous situations, or misuse of funds. These are all issues that need to be discussed and agreed.

9.6.3. Although it is unlikely, it is possible that the Support Plan will create risks that are not identified in the Plan, with the consequence that the Plan is agreed, and funding released, leading to serious problems later on. For this reason it is very important that the system includes a route through which the funding agency can obtain information about the individual in addition to the information included by the individual in their Support Plan. The structure we have proposed leaves State human services with the responsibility to gather and provide this information. It is very important that this duty is not given to independent planning support services, as it would pervert the role of these services, making them agents of the fund-distributing agency.

10. Productivity Commission Issues: How should the scheme be governed? By whom?

10.1. The Workshop Participant Group had strong views about the need for the establishment of an independent national body, or a statutory authority) responsible for the governance of a new disability support scheme. Article 33.3 of the UN Convention states that *"... persons with disabilities and their representative organisations shall be involved and participate fully in the monitoring process".* Key features of such a body would be:

- A Board is made up of a majority of people with disabilities and DPOs who are representative of key constituencies across the nation. Representation would also need to take into account the need for gender equity and input from indigenous people and people from culturally diverse backgrounds.
- It would make higher policy level funding distribution decisions.
- It would support resourcing of local/regional disability resource centres that would play a key role in providing independent advice and could support development of initiatives at the local level that would enhance effectiveness of individualised funding allocation. Funding (in part) for such activities is already present in some jurisdictions such as Victoria and West Australia.
- Costs of operating the Board would be funded through this scheme by Government, taking into account the full participation costs for board members and payment of sitting fees.
- It would have a research and development role to drive significant cultural paradigm change around disability support.
- This body would be underpinned by specific enabling legislation and report against UN Convention on Rights of Persons with Disabilities based performance measures. This would include funding for an independent complaints and appeals body.
- Body to be reviewed regularly by relevant administrative review body.

10.2. PWD shares the views of the Workshop Participant Group, and recommends a new Australian Disability Support Authority, which is constituted primarily by people with disability, representative organisations of people with disability, and representatives of families and carers of people with disability. This authority would have the range of responsibilities for the distribution of the funds to ensure that people with disability are adequately supported across the country, and would operate according to the new legislative and regulatory frameworks which are foreshadowed in the 10.1 above.

10.3. PWD is very supportive of a governance mechanism that will deliver individually funded and self-directed support. It accepts overseas opinion that important to this goal is governance by people with disability, and by representatives of families and carers of people with disability, at all levels of decision-making.

10.4. The governance structure of the crown agency in the province of British Columbia, Canada, which administers funds and oversees services to people with developmental disability is called Community Living British Columbia (CLBC). In its initial form the governance structure of CLBC was required to have 50% plus one of its Board members either a person with disability, or a family member or carer of a person with disability. In addition, in the local areas where the authority has staff working on the ground, there are advisory bodies made up of suitably experienced and skilled people with disability and family members and carers. This model replaced the previous government department which oversaw disability services, and represents one example of a statutory authority which has the potential to include people with disability at all levels of decision-making.

10.5. The authority must ensure there are mechanisms for local decision-making by the advisory groups of people with disability, and families and carers of people with disability, in particular to contribute knowledge and expertise about local conditions, gaps and resources, which need to be taken into account when eligible individuals living in those areas are negotiating their funding and support arrangements with authority staff.

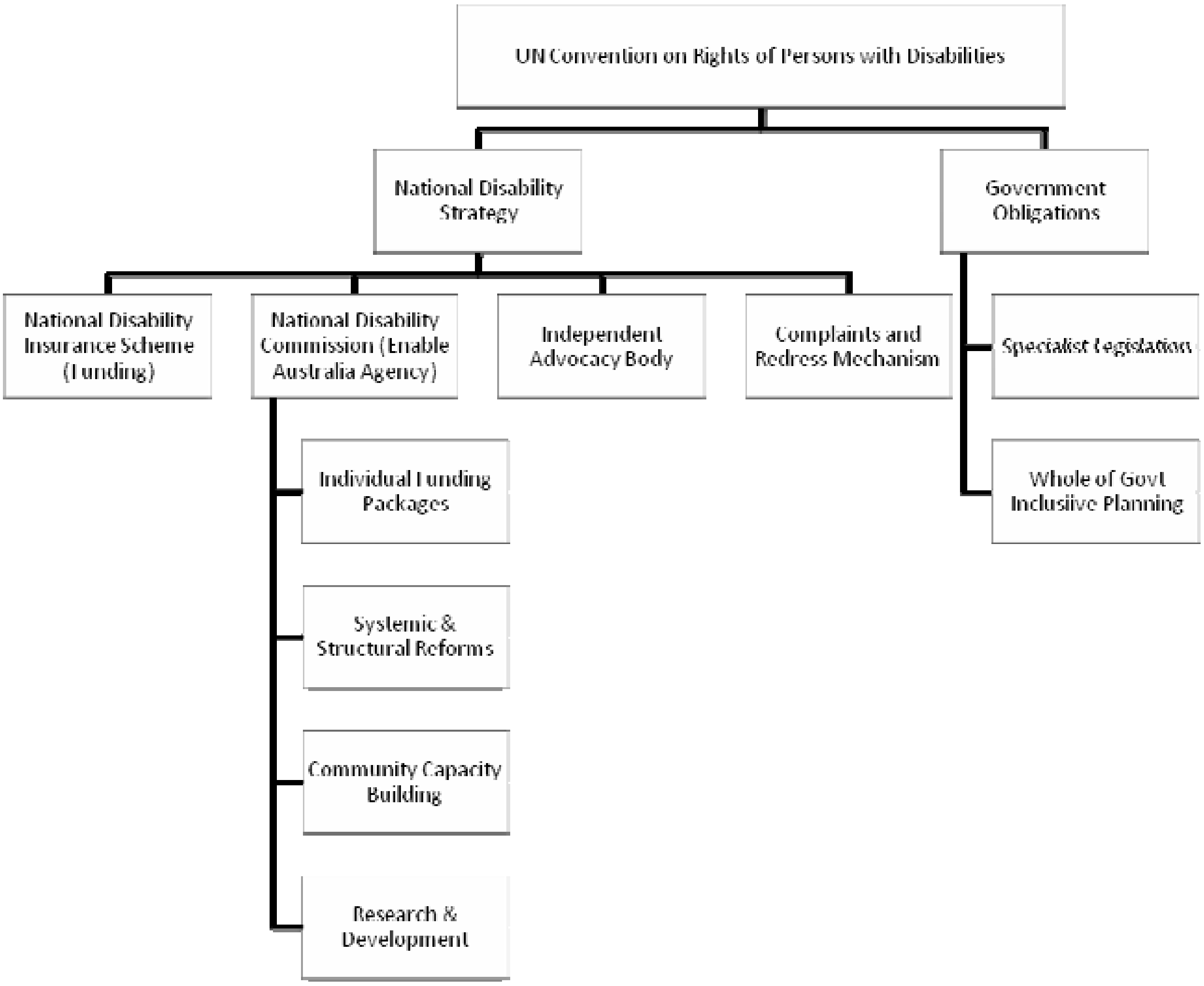
10.6. The new authority must value primarily the decisions made by the individual with disability who is in receipt of the support, and make decision-making, both as a means to control supports, and as an end in terms of the self-determination of the person in the community, as one of the principal outcomes it must achieve for all of its consumers.

10.7. The new authority must make available funds for research. These funds need to be distributed to undertake research on topics that are identified by the authority (if it is governed by people with disability, and by representatives of the families and carers of people with disability), which is informed by the lived experience of disability. Ideally this will be in the form of an allocation of funds, some of which is made available by tender for already specified research projects, and some for proposed independent research, which broadly addresses criteria and priorities specified by the authority that relate to improving the lives of people with disability. It is PWD's preferred position that funds not be expended on a new research centre, but that they be used to bolster and improve the existing research centres across Australia which have disability as their focus.

11. Productivity Commission Issues: Where does the proposed scheme fit with other government responsibilities to support the full inclusion of people with disability?

11.1. PWD firstly endorses the position taken by the Workshop Participant Group, in response to this issue. The group has proposed the following:

> A new scheme for funding disability support can't be expected to address all the issues that impact on people with disabilities. Ongoing structural reform work to address systemic barriers and remove discrimination needs to be properly funded and is not the direct task of a national disability support scheme.
>
> This chart sets out how the proposed scheme might sit alongside other areas of action to promote the rights and full participation of all people with disabilities and their families:



****Description of chart for screen readers**

The chart inserted at this point sets out a hierarchy for elements discussed in this framework document and graphically represents how the elements fit together.

- *Level 1 Text Box – UN Convention on Rights of Persons With Disabilities*
- *Level 2 Text Boxes – Text box to the right is Government Obligations and listed under it are text boxes for a) Specialist Legislation and b) Whole of Government Inclusive Planning.*
- *Level 2 Text Box – Text box to the left is National Disability Strategy*
- *Level 3 Text Box - Under National Disability Strategy are four text boxes that have the following text – a) National Disability Insurance Funding, b) National Disability Commission (Enable Australia), c) Independent Advocacy Body, and d) Complaints and Redress Mechanism.*
- *Level 4 Text Box – Under the National Disability Commission (Enable Australia) text box are four elements: a) Individual Funding Packages, b) Systemic and Structural Reforms, c) Community Capacity Building, and d) Research & Development.*

11.2. Section 7.3.1 has identified the important link between social security pensions and benefits, which adequately identify and compensate for costs associated with disability, and the new scheme, which essentially accommodates higher support needs; and the need for entitlement to both of these to enable people with disability to have access to supports and resources that will place them on an equal footing with other members of Australian society. There must be further reform of Australia’s social security system, in line with the submission made by the Australian Council on Social Services (ACOSS 2010), in response to the recommendations made by the Henry Tax Review. In short, PWD endorses the call to increase benefits and make a flatter rate of benefits and pensions, and onto this to build additional allowances and entitlements which directly and effectively address particular financial barriers to people with disability participating in the community (eg increased rental for accessible housing, additional mobility costs due to lack of accessible public transport, other technological requirements due to delivery of information in non-accessible formats).

11.3. In Section 7.3 we have identified the need to include in the new scheme people with psychosocial disability, who are eligible on account of their support requirements. PWD recognises that the exclusion of people with psychosocial disability from the current disability service system, and from regulation under disability services legislation, is largely a result of bureaucratic demarcation. The administration of programs, services and supports for people with psychosocial disability under the various health departments in Australian jurisdictions has, we believe, led a predominantly medical and clinical approach to addressing the needs of people who utilise mental health services, and to the administration of some community-based services (such as the Housing Accommodation and Support Initiative in NSW) without reference to the rights-based disability service legislation that regulates other, similar services to people who are otherwise differentiated by disability. Further, PWD recognises that there is a growing international movement amongst mental health consumers to have access to the same entitlements to individualised funding and self directed supports as enjoyed by other people with disability (and social support recipients), and that in jurisdictions such as the UK the legislation enables people in this category to access funds in the same way as do others. It is essential, therefore, that the Inquiry look into ways in which the community-based supports, which address the everyday needs of people with psychosocial disability, can be brought under this scheme, and be separate to the administration of health-focused services.

11.4. How a new scheme should be implemented. The Productivity Commission is also looking at how we should move forward to introduce a new scheme. Pressure to rationalise expenditure on such a scheme will always be a challenge. It will be important to position this scheme strongly within the government's obligations to implement the CRPD. The CRPD requires much more than access to services and is based on supporting “full and equal enjoyment of all human rights by all people with disabilities”.

While the Convention provides for “progressive realisation” of social, cultural and economic rights, it is the view of people with disabilities and their organisations that Australia has the economic capacity to address these responsibilities immediately.

People with disabilities and their organisations will need to advocate strongly for implementation that is not compromised by rationing of funding or threatened by resistance to systemic reforms of disability support.

The following points suggest some of the steps that might need to be taken:

- Identify all existing disability support funding and administration funding provided through all levels of government. These include – National Disability Agreement, HACC & Mental Health.
- Consultations with consumer advocacy groups in aged care sector about whether people with ageing related disability should be part of this reform and at what stage should this happen.
- Identify capacity of existing funding to address current demands for support.
- Introduction of a new dedicated tax to address any shortfall in addressing current demands for disability support for all who meet eligibility requirements. This dedicated tax should include existing expenditure.

- Develop individualised funding packages for eligible target group commencing with current recipients of funding and then addressing unmet needs through a significant investment of new funding.
- Adopt learning from current initiatives that have already been commenced in various jurisdictions (esp. Victoria, West Australia, NSW and FaHCSIA Business Services reforms) and utilise experience from working models in other countries.
- Significant investment required in workforce development and training to support a significant cultural paradigm shift in disability support. There is a need to better understand how far market needs will drive this reform and how much intervention from a more managed approach is needed to ensure sustainability of the workforce. Article 4 of the UN Convention should be used as the basis for professional training and development for support workers and their agencies if we are to achieve cultural change in disability support.
- Diverse opinions were expressed about the merits and risks of professionalisation and accreditation of the disability support workforce. This issue requires further attention and research.
- Develop a collaborative approach with relevant unions to address current and projected Occupation Health and Safety barriers and associated risk management culture in agencies that provide disability support.

11.5. Investment in Housing. This submission has already identified the need for there to be a holistic approach to disability issues, and cooperation between government departments, across jurisdictions, and also greater efforts to reduce the barriers that people experience in the community and in private enterprise. A significant barrier to the successful implementation of self-directed supports is the poor supply of suitably accessible and affordable housing across Australia. This needs to be addressed, with significant lobbying and advocacy from the authority, but perhaps better taken up by the Office of Disability in each jurisdiction, who would have a responsibility to work across departments and more broadly in the community to ensure that barriers to the inclusion and participation of people with disability are systematically identified and removed. People with disability need to live in a range of ordinary housing, not specially designed “accommodation”, and this new scheme will provide the relevant supports to people who can access housing, but must not be drawn into costly capital development of design-compromised, specialist facilities.

11.6. Strengthening the human rights framework. Without a robust framework of human rights, issues related to people with disability tend to be relegated to charity, and responses become reactive, compromised and inappropriate. The ratification of the CRPD, and the Australian Governnment’s signing of the Optional Protocol, must be followed up with a progressive program of legislative and regulatory reform, so that the new scheme is but one of a range of activities that are working toward a more inclusive Australian society. The Commonwealth Disability Services Act is clearly in need of significant reform, both to bring it up to meet Australia’s compliance needs under the CRPD, and to accommodate the increasing numbers of people who require the type of support that the legislation was enacted to regulate.

11.7. Bureaucratic reform. The current disability system is administered within a range of complex Commonwealth and State/Territory programs, by multiple departments that answer to different Ministers, again Commonwealth and State/Territory, and is characterised by complexity, over-bureaucratisation and, ultimately, disarray. A single, nationally administered authority, needs to cut through this, by focusing decision-making on the individual at the local level.

12. References and acknowledgements

Australian Council of Social Service (ACOSS) (2010), Summary of ACOSS proposals, Henry Review recommendations and the Government's response: social security reform available, [online]:

http://acoss.org.au/images/uploads/Henry_Review_-_evaluation_of_socsec_proposals.pdf

The following submissions to the Productivity Commission inquiry into disability care and support are acknowledged in this document:

- In Control Australia (yet to be submitted)
- National Ethnic Disability Alliance (NEDA) (yet to be posted)
- Mental Health Coordinating Council (MHCC) (yet to be posted)
- Women with Disabilities Australia (WWDA) (Submission 260)
- People with Disability Australia (PWD) – Summary Submission July 2010 (Submission 171)
- The Australian Human Rights Commission (AHRC) (Submission 72)