ADVOCACY TASMANIA INC

SUBMISSION TO
PRODUCTIVITY COMMISSION INQUIRY INTO

DISABILITY CARE AND SUPPORT

AUGUST 2010

EXECUTIVE SUMMARY

Any attempt to transform Australia's disability service system without reference to its near-neighbours the aged care and mental health sectors will serve only to entrench existing inefficiencies and inequities. Our aged care system is a disability system with an age-related eligibility criterion bolted on, not a conceptually distinct arena. So too with Australia's threadbare patchwork of supports for those with disabilities linked to mental health issues. A transition to a true 'social' model of care will require that we abandon attempts to structure eligibility for support around the 'condition' that contributes to disability. Instead, our focus must be on the specific ways in which the individual is constrained from living a life that is meaningful, active, social and contributory. We argue for the development of an integrated national care[1] system, and point to the important learnings from recent UK developmental work.

The existing care system in Australia fails to uphold basic human rights. Our submission points to important rights frameworks – especially the UN Convention of the Rights of People with Disabilities – and urges the Australian Government to recognise its formal obligations to develop a national care system that is demonstrably compliant with these rights frameworks.

Australia's care system is also a *market* – an arena for the interplay of supply and demand forces. Like all markets, the allocative efficiency of our care system is constrained by restrictions on the range of market actors (buyers and sellers) and by inadequacies in the information available to those buyers and sellers as they make transaction choices.

This submission argues for a significant shift in both of these constraining factors. We argue for a care system comprised of more 'buyers' and more 'sellers' via a far greater emphasis on individualised funding approaches. We further argue for a concomitant emphasis on the support structures required for individuals and their families to participate as assertive, informed consumers. This second shift – to a comprehensive, coherent infrastructure of supported decision-making – will be required even if the current 'supply' system of care continues unchanged, but will be especially important as we move towards a greater diversity of service providers.

It will come as no great surprise that our submission focuses on the roles played by *individual and systemic advocacy* in supporting the effective flow of market information. Advocacy organisations such as our own have accumulated decades of experience in supporting consumers and carers to negotiate a flawed and inadequately-resourced care system. That experience reinforces our assertion that the advocacy process does two fundamentally important things:

- it assists the consumers of services to understand the choices available to them, to optimally participate in decisions about those choices and to effectively communicate their decisions to service providers; and

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[1] References to 'care' through this submission are taken to cover the broader concept of 'care and support' referenced in the Inquiry title, which we regard as including any good, service or environmental adaptation that assists people with disabilities to overcome limitations to carrying out activities of daily living and in participating in the social, economic, cultural and political life of the community. We acknowledge at the outset that many people with disabilities, and many who work in the disability sector, find the term 'care' patronising and disempowering. While we share those concerns, it is apparent that no consensus as yet exists in regard to an acceptable alternative term.

- it assists service providers (and system-level decision-makers such as funding agencies) to better understand the needs of consumers.

Individual advocacy supports consumer decision making and communication and simultaneously enhances service provider information about consumer needs. Systemic advocacy – based on the thematic compilation of recurring access barriers and quality failings evident across individual advocacy contexts – supports continuous improvement processes at the service provider and system levels. That systemic advocacy also contributes to service development – the recognition by service providers and system-level decision-makers that service gaps (market opportunities) exist. We argue that a comprehensive national advocacy program be understood as an essential *infrastructural* component of the proposed care system.

Summary of Recommendations

The Australian Government, in developing a comprehensive response to the deficiencies in existing care and support provided to Australians with disabilities, is urged to:

1. **Ensure that all elements of the proposed service system are compliant with the United Nations Convention on the Rights of People with Disabilities. (p9)**

2. **Recognise that the aged care service system and key elements of the mental health support system are best understood as important subsets of a broader disability service sector and that a comprehensive, integrated national care system is required. (p7)**

3. **Ensure that the concurrent Productivity Commission inquiries into aged care and disability are developed in such a way that the option of a comprehensive, integrated care system is appropriately examined. (p7)**

4. **Ensure that all proposed changes to Australia's disability system directly contribute to the social inclusion objectives adopted by the Australian Government. The framework outlined in the South Australian *Activating Citizenship* process should be closely examined with a view to translating key elements to the national level. (p11)**

5. **Develop a suite of service options based around the concept of individualised funding to consumers as a means of maximising consumer choice and decision-making control. (p15)**

6. **Recognise that an important component of the change-management strategy required for Australia's care system is the further development of an infrastructural layer of independent, professional and accessible advocacy services. (p17)**

A. INTRODUCTION

1. About Advocacy Tasmania Inc

Advocacy Tasmania Inc (ATI) has for the past twenty years provided independent, professional advocacy services across Tasmania. ATI is a non-government organisation funded by the Australian

and Tasmanian governments to support consumers and carers in their interactions with Tasmania's disability services sector, residential and community aged care sector, mental health sector and alcohol, tobacco and other drugs sector. In addition to this array of individual advocacy services, ATI has a strong track record in systemic advocacy and is frequently invited to contribute to system reviews and associated reform processes. Our work across the above service sectors – unique among Australia's advocacy organisations – provides us with valued insights into the different (and shared) experiences faced by consumers and carers. The ATI governing Board of Directors is comprised entirely of consumers and carers of these service sectors.

The past decade has witnessed an important transition within ATI from essentially *reactive* modes of operation to *proactive* ones. In practice, this means supporting consumer decision-making processes at all points of the consumer trajectory – from initial assessment and care planning processes, through the negotiation of service delivery outcomes, to more remedial approaches when the type, quality or quantum of service delivery is inappropriate for the goals of the consumer.

2. The Inquiry: Issues to be addressed by Advocacy Tasmania

The scope of the Productivity Commission's inquiry is substantial. Almost two hundred questions were formally posed in the Commission's Issues Paper, with no duplicated or trivial questions among them. Understandably, the ATI submission will not attempt to address the full range of issues canvassed. Instead we will focus on areas where we are confident we can make an expertise claim arising from our experience in providing advocacy services in the disability sector (and related sectors). Accordingly, most of our attention will be concentrated on the following components of the second major Term of Reference provided to the Commission:

> *"2. The Commission is to consider the following specific design issues of any proposed scheme:*
> - *Eligibility criteria for the scheme, including appropriate age limits, assessment and review processes*
> - *Coverage and entitlements (benefits)*
> - *The choice of care providers including from the public, private and not-for-profit sectors*
> - *The implications for the health and aged care systems"*

B. THE TRANSITION TO A COMPREHENSIVE, INTEGRATED CARE SYSTEM: THE AGED CARE – DISABILITY-MENTAL HEALTH NEXUS

1. Parallel inquiries

ATI notes that, parallel to this important inquiry, the Productivity Commission is conducting another vitally important investigation into *Caring for Older Australians*. That inquiry has rather narrower terms of reference, but the Commission's Issues Paper formally poses the question of whether it is sensible to continue with separate aged care and disability service systems, or whether "a broader conception of care and disability policy [would] be more appropriate, with the needs of the aged being one part of this continuum?" (CfOA IP, p15).

The Terms of Reference for the *Disability Support and Care* inquiry include a requirement that the Commission consider design issues (for the envisaged disability care system) that take into account impacts on the aged care system. The Issues Paper for that inquiry raises – in the context of a broader discussion about the issue of eligibility – three possible options for dealing with what is described as "natural ageing". Remarkably, all three options would retain the concept of chronological age as a component of the eligibility mix. One of these suggested options begins promisingly enough – "funding and managing the provision of services for all sources of disability at all ages …" – only to revert to a similar age-based qualification: "… with the exception of certain conditions that are strongly related to ageing and that occur in people after middle age" (IP, p19). We contend that this approach is flawed in two important respects: the focus on "conditions" and the notion that age is a defining element in our understanding of the need for care and support.

For Advocacy Tasmania, the answer to the vitally important question posed by the *Caring for Older Australians* inquiry is that a single, integrated care system is both possible and desirable. ATI contends that the separation of the two service systems owes much more to history than it does to logic. What we know as the aged care system is in fact a second, parallel disability care and support system. Individuals do not and should not receive services purely on the basis that they have reached a nominated age point in the life-course.[2]

In both systems, services are allocated on the basis of need, understood as some form of core activity limitation. The term 'frail aged' is often invoked in contexts where no specific condition is identified as contributing to an older person's core activity limitations. Ultimately, though, it is the core elements of the 'frailty' – lessened core strength, stamina, balance, etc – that leave the individual less able to perform core activities. In this sense, frailty is a variation on disability, not a meaningful category in its own right that warrants a different approach to care and support.

A merged service system would help to dispel two important misconceptions – one from each of the current systems. First, a comprehensive approach to care would keep the focus on the specific disabling impacts – the actual activities that are limited – rather than on the 'condition' deemed to underpin those activity limitations. Second, a melded service system would of necessity acknowledge the full continuum of conditions that contribute to disability[3]. This would allow us to escape the artificial rationing device prevalent in the current disability system – the dominant focus on only those who are deemed to have a 'severe or profound' disability. ATI asserts that if we are to develop a service system that takes seriously the stated social inclusion goals of the Australian Government (and indeed of most state and territory governments), then the full continuum of disablement must be addressed. As we discuss further in Section C below, the ability of many Australians to engage meaningfully as citizens is constrained by the impacts of conditions that are unlikely to be recognised as 'severe or profound' but which nevertheless have a severe and profound impact in excluding them from activities and relationships that most of us take for granted.

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[2] While we characterise the aged care system as a "second" disability system, it is far from being *secondary*. In our own state of Tasmania, just over 6,100 individuals receive formal disability services funded via Commonwealth-State programs. However over 25,000 Tasmanians receive care and support from Home and Community Care Program services or via CACP / EACH packages.

[3] Note that movement towards an integrated care system is very different from abandoning age-appropriate approaches to care and support. Integration of the systems must not be used as an excuse (for example) for the inappropriate placement of younger disabled persons in residential care settings suitable only for older persons.

Our advocates are regularly involved in providing support to clients who are negotiating the difficult transition from the disability service system to the aged care system. Our advocacy work confirms that:

- there are substantial inequities in the ways in which the disability and aged care systems respond to individuals with the same levels of need, and
- transitions between the two systems are handled poorly, frequently resulting in a reduction of services to individuals.

ATI is familiar with instances of individuals who have been denied continuity of important service elements for no reason other than that they have reached the age of 65 and eligible to access residential aged care[4]. It is difficult to imagine a more blatant and callous example of government-sanctioned discrimination than a withdrawal of services based solely on age rather than need.

So too with the intersection between the existing disability and aged care service systems and the mental health system. While the stated eligibility criteria applying to a number of disability and aged care programs include references to "psychiatric disability", suggesting a level of integration, the reality is otherwise. Programs funding community-based and residential-based supports to individuals with mental health issues have typically been developed separately from 'mainstream' disability and aged care programs. This parallel program development has largely been in response to the failure of these other programs to address the needs of those with mental health issues, even when such issues co-occur with intellectual or physical disabilities. The official rhetoric that mental illnesses and disorders are just another category of disability is simply not matched by the practices of funding agencies and (almost all) service providing organisations.

2. Toward a National Care System

In considering the elements of a national, integrated care system, much can be learned from the important preparatory work undertaken by the UK Government in recent years, culminating in the *Building the National Care Service* report published last year (HM Government, 2009).[5] Faced with a similar array of system failures, the UK Government facilitated a wide-ranging national discussion (with over 68,000 British citizens participating in what was promoted as 'The Big Care Debate'), the result of which was a significant consensus about the need for a comprehensive, integrated service system. This national conversation covered not only the service-delivery structure deemed to be necessary, but an equally ambitious investigation of the possible mechanisms for funding the proposed system. (While our submission will not address the intricacies of national funding mechanisms, we note that the Australian debate has been rather narrower than the corresponding British variant. Specifically, a key focus of the UK deliberation has been on ensuring a level of inter-generational equity, with a consequent emphasis on inheritance taxes as one part of the funding mix. There does not appear to be much political appetite for such a conversation in the Australian political community.)

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[4] One example was of an ATI client who had been funded by the state disability services agency to travel interstate, once a year, to visit family members. This funding was withdrawn despite the underlying need – continuity of family contact – remaining after the client moved in to residential aged care.

[5] Note, however, that it is currently unclear which elements of the proposed service structure will be progressed by the new UK government.

The UK report proposes six key organising principles for a national care system[6]:

- Accessibility – offering clear and comprehensive information and, where necessary, support for individuals to take decisions;
- Universality – supporting all eligible persons with a comparable range of entitlements;
- Affordability – such that provision of services is based solely on need, not on ability to pay;
- Choice and control – respecting the right of individuals to take key decisions about their lives;
- Support of families and communities – recognising the roles that they play in enabling individuals to live their lives fully;
- Partnership – meaningfully involving the range of different organisations that contribute to the care and support system.

ATI endorses these principles as essential building blocks for Australia's care system. We also support the basic architecture proposed for the UK system – the so-called "six pillars" below:[7]

- Prevention and wellbeing services to keep citizens independent – enshrining a focus on preventative measures that include providing support when a care need first arises as a means of stopping problems from escalating.
- Nationally consistent eligibility criteria – offering genuine portability across jurisdictional boundaries and a level of certainty such that individuals/families can confidently engage in the same sort of long-term planning that we now encourage in other realms (e.g., superannuation).
- Information and advice about care and support options – including, where needed, the provision of independent, professional advocacy supports.
- Personalised care and support, through a personal budget – offering individuals the choice between an entitlement that they can use to pay for their needs or a direct payment to a service provider.
- Joined-up assessment processes – making it simpler and easier for individuals to access services.
- Fair funding, with collective, shared responsibility for paying for care and support – affordable and marked by genuine intergenerational equity.

A merged care system would provide the potential for important cross-sectoral learnings. For example, in Section D below, we argue for a greater emphasis on the use of individualised funding packages as a mechanisms for increasing consumer choice and decision-making control. For all its manifold faults, Australia's disability service systems have made much more progress in exploring the use of individualised funding than have the aged care or mental health sectors, and there is considerable scope for overdue cross-fertilisation.

Advocacy Tasmania contends that to fail to address this integration agenda is only to postpone the inevitable. The single most important 'driver' of the increasing prevalence of disability in the Australian community is the ageing of the population. We know from numerous studies of disability

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[6] These principles are adapted from *Building the National Care Service*, 2009, p13.
[7] This section draws on the discussion in *Building the National Care Service*, 2009 on pp14-16.

prevalence that it is in the older age groups that disability is most common – 22.5% of over-65s and 34% of over-75s having a severe or profound core activity limitation (AIHW, 2003; ABS, 2007). We also know that of those Australians who have a disability, 62% of those with *multiple* disabilities will be aged over 65 (AIHW, 2009, p3).

This presents a major challenge for service planning. Here in Tasmania, the projections offered by the Tasmanian Government's Demographic Change Advisory Council suggest that the over-65 population will double in just twenty years and that within that group the proportion of over-75s will have also have grown. If the AIHW and ABS are correct, a quarter of Tasmania's projected additional 65,000 over-65s will have severe or profound core activity limitations. Put bluntly, a state that currently provides assistance to just over 31,000 individuals will need to find approximately 19,000 additional packages of care – just to address the impact of ageing.

> **Recommendation: Recognise that the aged care service system and key elements of the mental health support system are best understood as important subsets of a broader disability service sector and that a comprehensive, integrated national care system is required.**

> **Recommendation: Ensure that the concurrent Productivity Commission inquiries into aged care and disability are developed in such a way that the option of a comprehensive, integrated care system is appropriately examined.**

C. THE TRANSITION TO A RIGHTS-BASED SYSTEM: BUILDING AN INTEGRATED CARE SYSTEM THAT SUPPORTS HUMAN FLOURISHING

1. The rights of Australians with disabilities

On 21 August 2009, Australia ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). That ratification obliges the Australian Government:

> (a) To adopt all appropriate legislative, administrative and other
> measures for the implementation of the rights recognized in the present
> Convention;
> (b) To take all appropriate measures, including legislation, to modify
> or abolish existing laws, regulations, customs and practices that constitute
> discrimination against persons with disabilities;
> (c) To take into account the protection and promotion of the human
> rights of persons with disabilities in all policies and programmes; (United Nations, 2007, p5)

in order to give effect to the stated principles within the Convention, which include:

(a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
(b) Non-discrimination;
(c) Full and effective participation and inclusion in society;
(d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
(e) Equality of opportunity;
(f) Accessibility. (United Nations, 2007, p4)

It is important that we recognise that Australia's ratification of this Convention (and the Optional Protocol relating to a complaints-handling process) brings with it more than just the moral obligation to pursue the above principles. There is now a formal legal obligation that creates a solid platform for actions by individuals and groups who believe that their rights have been compromised or denied. Planning for our future national care system must be continually guided by the question 'in what ways will these changes ensure compliance with the spirit and the letter of the UN Convention?'. To fail to orient our care system to a rights framework would be to fail the first test of sustainability, as non-compliant programs and services will undoubtedly face legal challenges from an increasingly assertive consumer movement.[8] We acknowledge that resource constraints are recognised by the UN as relevant to the obligations of signatory nations. Sadly, there are many nations that will not have the resources required to fulfil their obligations. Australia, though, is not one of those nations.

> **Recommendation: Ensure that all elements of the proposed service system are compliant with the United Nations Convention on the Rights of People with Disabilities.**

2. Social inclusion – from slogan to system architecture

The existing care system fails Australians on a number of levels. Structurally, the focus has been – both in residentially-based services as well as community care services – on decision-making processes that deny Australians with a disability the right to make important choices about their care. The provision of block-funding to service providers, rather than personalised budgets to consumers, has reduced the choices available to consumers, denying them fundamentally important forms of control over their own lives. We assert that this is a form of *de facto* substitute decision-making, applied in contexts where independent decision-making and forms of supported decision-making are both possible and desirable.

At a service level, too few options exist for the support of people with disabilities to continue (or further develop) their interdependence with others, their social interaction and their connection to communities. The UN principle of "full and effective participation and inclusion in society" requires

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[8] Note that in other countries that have ratified the Convention, this reform-through-litigation process is well under way. The international context that arguably offers the closest parallel to the Australian sector is that of Canada. There, the Council of Canadians with Disabilities has tracked the early – and thus far successful – efforts by litigators to bring actions based on this human rights framework. Their survey and related documents can be found at
http://www.ccdonline.ca/en/socialpolicy/poverty-citizenship/social-judgment-social-exclusion.

a very different approach. Here, people with disabilities would be understood not just as individuals with rights and entitlements but as full citizens capable of fulfilling their civic responsibilities as part of their communities (and the governing structures for those communities). With appropriate support, they will be granted a 'right' they regard as crucially important – the right to discharge their obligations; to *give* to their communities rather than merely *receiving* from those communities.

In our earlier discussion of the need for an integrated national care system, we pointed to the intersection between the concept of social inclusion and the eligibility criteria that apply in current and prospective service sectors. We argued that a narrow focus on only the 'severe and profound' end of the disability continuum would neglect important constraints currently imposed on many other Australians with disabilities. Moreover, this focus would lead to a concentration on the (admittedly important) services required to assist individuals with aspects of daily living (e.g., personal care, home help) to the exclusion of supports that target the participation of the individuals in the array of social, cultural, economic and political activities open to other Australians.

What would a coherent social inclusion approach to disability look like? Much can be learned from the important contribution made by South Australia's Social Inclusion Board with its recent discussion paper, *Activating Citizenship: A Social Inclusion Approach for Disability in South Australia* (2010), prepared as part of that state's development of a broader disability strategic framework.

The broad goals of *Activating Citizenship* are reassuringly familiar: "that we move forward from exclusion and discrimination of people with disability to a fully inclusive and mutually supportive community that recognises individual talents, knowledge and skills ... that people with disability can fully participate in community life on their own terms ... [that] human rights are protected as a fundamental cornerstone of government disability policy and practice" (p7).

The South Australian approach goes beyond these laudable generalisations, however, articulating three main pathways to social inclusion. First, a focus on strengthening dignity, rights and protection is proposed, with a recognition that this will require a sound legislative foundation – including the role of the United Nations CRPD. Specific approaches are canvassed, including the role of advocacy services (see Section E below). The Discussion Paper also highlights the importance of independent complaints bodies as a key feature of a rights-oriented disability framework. Significantly, the Paper also proposes steps to minimise the reliance of consumers on any one single service provider, and argues for genuine choice: "Put simply, if a person is unhappy with the service they are receiving, they should have the choice to go elsewhere" (p14).

The second broad focus of *Activating Citizenship* is on "enabling communities" – contexts in which individuals with disability can, across the life-course, "seek satisfying and sustainable work opportunities, innovative educational opportunities, secure and affordable housing and accommodation, successful personal relationships, family life and a healthy and leisurely retirement" (p17). The Discussion Paper recognises that among the specific steps required will be the redesign of health services to promote linkages with the disability sector, improving linkages between disability services and relationship counselling, parenting and peer support, and providing additional supports within the workplace. The importance of civic participation is recognised in a series of proposals relating to access to the key 'spaces' of civic and cultural interaction, together with initiatives that promote and celebrate the civic participation of people with disability.

Third, the Discussion Paper argues for "shifting the focus from bureaucracies to citizens", recognising that "people with disability, families and carers have a voice in determining what services are needed and how they should be provided" (p34). At the core of this approach is service integration and simplification, and consumer input to continuous improvement processes within service systems. Proposals canvassed in the Discussion Paper include the development of "integrated service models to support people with disability who have other complex needs (e.g., mental health, drug and alcohol abuse)" and "promoting service delivery initiatives that take an assertive outreach approach, that is encouraging the establishment of services that go to the community – rather than having individuals come to them" (p36). An important related approach involves "developing performance indicators for all services and programs relating to people's aspirations and life-long goals as well as their needs" (p36).

At the core of the South Australian social inclusion approach is the notion of "personalising the approach to service delivery". This approach "promotes decision-making control by the individual and their family in determining what services and supports are provided and choice in who delivers those services" and "promotes and encourages training, mentoring or other activities so that an individual can develop the skills, capacity and confidence to be more active in the decision-making processes related to their care and support" (p41). The Paper goes on to offer a series of arguments for individualised funding models, arguing that such funding should be expanded and that further exploration should occur with regard to individualised funding models that are "premised on simplicity and ease" (p41).

We stress again that *Activating Citizenship* is at this stage no more than a Discussion Paper front-ending a strategic development process for South Australia. Nevertheless, the core ideas and many of the specific proposals merit close attention in the context of the Productivity Commission inquiry's key terms of reference.

> **Recommendation: All proposed changes to Australia's disability system should directly contribute to the social inclusion objectives adopted by the Australian Government. The framework outlined in the South Australian *Activating Citizenship* process should be closely examined with a view to translating key elements to the national level.**

D. THE TRANSITION TO A FUNCTIONING MARKET: BUILDING GENUINE CHOICE FOR CONSUMERS

The Issues Paper poses the important question "Are there ways other than individualised funding that empower people with disabilities and their families?" (IP, p25). A mature and comprehensive care system for Australia will encourage a central focus on the consumer as the primary decision-maker. *This primacy of the consumer will emerge not just as a rights issue, but as a necessary foundation for the development of responsive, innovative and accountable services.* A care system driven by consumer choices will also attain a greater level of legitimacy – it will be supported by the wider Australian community as a significantly more transparent use of the public funds involved. The concept of 'choice' has within it two fundamentally important dimensions: diversity and capacity. There can be no real choice if the options on offer are essentially identical. Equally, there can be no real choice if the consumer is unable to take meaningful decisions and communicate those decisions. It is our contention that the

current Australian care system is deficient on both dimensions – it offers too little real diversity in care options and offers too little support for consumers to be other than passive recipients of those care options.

This central focus on the consumer will take the form of enhanced decision-making control in all aspects of the consumer 'experience'. Four key phases are examined below: initial access; engagement with service providers; receipt of services; and participation in service/system improvement. The crucially important role of individualised funding approaches is then discussed.

1. Consumer decision-making in the access phase

Individuals with a disability need access to information about service *models*, about service *providers*, about the *rights and responsibilities* associated with services, about *costs*, and about the systems that are in place to assure quality. As the number and range of service models and providers increase, consumers will also need independent, trustworthy sources of information to assist them in comparing the actual performance of the options they are considering.

Mature, efficient markets depend on consumers having access to reliable information about the choices they face. In the existing care system, not only are there very few choices available to consumers; consumers also face a struggle to obtain and interpret information about the services on offer and about their eligibility to participate in particular programs. A consistent role for ATI advocates is that of assisting older persons and their families to negotiate and understand the often-inadequate information resources currently available.

2. Consumer decision-making in the engagement phase

The engagement phase of the consumer journey involves direct contact with a chosen service provider (or, more likely, one chosen for them). Here, the key processes are assessment and care planning.[9] The current system is based heavily on *de facto* substitute decision-making, rather than supported decision-making: the assessment process (and the organisation responsible for carrying out the assessment) are determined by policy, not by the consumer. Few alternatives exist to allow consumers to engage a different assessment process/provider. While "getting a second opinion" might be recommended in our primary or acute health systems, no such option is available to most people with a disability in relation to their care needs.

So too with care planning. Many service systems apply an 'algorithm' approach – a formulaic translation of assessed need into a standard package of services. Our advocates devote far too much time to assisting individuals in their efforts to vary care plans that had failed to take into account the express wishes of the consumer. We acknowledge that some service providers have made significant advances in this regard, but overall there is little understanding of the capacity of individuals with a disability to participate in, and markedly improve, these planning processes.

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[9] In the aged care system, assessment is provided in a range of contexts, some directly involving the service provider, others performed by specialist units (e.g., ACAT).

3. Consumer decision-making in service delivery

Again, many decisions about the minutiae of service delivery (which care worker, at what hours, providing exactly what services, etc) are determined by service-wide or system-wide policies – not by the consumer. For consumers, these details are vitally important. For consumers, being denied a say is even more important. We recognise that there will always be efficiency arguments that can be made in relation to the specifics of service delivery – that, for example, the work of paid carers is more cost-effective if spread across the working day with the result that not all consumers can expect their service at a time of their choosing. However, it is often the case that consumer involvement in service planning (see 4 below) can generate imaginative responses to these efficiency imperatives.

4. Consumer decision-making in service/system improvement processes

Low level forms of consumer engagement in service and system quality improvement processes are now relatively common. Many organisations routinely involve consumers in reviews of service quality, often as part of external accreditation processes. Less common, however, is the engagement of consumers in formal decision-making contexts that directly impact on services. As the key stakeholders in all governance and management decisions relating to care services, consumers should have a central role. ATI acknowledges that the development of genuinely representative structures, whether at local, regional, jurisdictional or national level, is a challenging and resource-intensive process. These tasks need to be tackled with skill and sensitivity if the resulting contributions to decision-making are to be seen as legitimate.

Without 'learning loops' that centrally involve people with disabilities, the capacity of services to improve their service delivery is significantly limited. Just as important, these feedback mechanisms are essential for service development processes, not just service improvement ones. That is, consumers are able to assist service providers (actual and prospective) to recognise 'gaps in the market' – new service modalities that could address unmet needs within sustainable business models.

5. The role of personalised funding approaches

The block-funding of service providers will continue to be a fundamentally important component of any future Australian care system. Some service models can only be sustained on the basis of block-funding. Indeed a continued focus on strategic block-funding will almost certainly be necessary to ensure that an adequate range of choices is available to consumers.

We should recognise, however, that block-funding is a form of substitute decision-making. It is a mechanism whereby funding agencies make an assessment of aggregate consumer needs, make a determination of the service models they (the funding agencies) believe are most appropriate to meet those needs, and choose the service providers they believe are best placed to deliver the identified services. That is, three kinds of decisions (about need, about service model, and about service provider) have been taken *on behalf* of the consumer, not *by* the consumer.

Advocacy Tasmania acknowledges that there will be instances where, for reasons of incapacity, substitute decision-making is required. However we assert that the vast majority of individuals are

able to participate in at least some elements of decision-making processes, given appropriate support. A major focus of our work is supporting individuals so that they can optimally participate in these decision-making processes. While those support roles can be challenging, the real challenge arises from the reluctance of services/systems to acknowledge that consumers have the right (and the ability) to contribute to this decision-making.

The Issues Paper poses the question in this form: "How can people with disability and their carers have more decision-making-power in a national disability scheme?" (IP, p24). Our response is to argue that *a major shift to individualised funding approaches will be necessary if we are to remedy (a) the paucity of choices available to consumers; and (b) the systemic failure of block-funded service providers to offer genuine decision-making opportunities to consumers.*[10]

We note that the parallel Productivity Commission inquiry into *Caring for Older Australians* poses a more direct question on this issue: "Should subsidies that 'follow' approved clients be paid to providers or should care consumers be given the choice of receiving such payments first to promote a greater capacity to exercise choice?" (CfOA IP, p20) This distinction – between 'consumer directed' variants and payments direct to consumers – is an important one. To date, the default position of many funding agencies has been payment to the service provider, leaving consumers will very little say in how the funding will be disbursed[11]. ATI contends that this approach must change. The default assumption must be that the individual (supported by family members and, where appropriate, advocates) can take decisions about the disbursement of funding. The onus should not be on the individual to demonstrate such capacity.

The Issues Paper poses two other important questions: "What have been the experiences overseas and in Australia with individualised funding, including their impacts on outcomes and costs? What lessons do these experiences provide for adopting this approach as an element in a national disability scheme?" (IP, p24). These questions can now be answered with confidence. The comprehensive report commissioned by FaHCSIA and prepared by the Social Policy Research Centre (Fisher et al, 2010) reviews the experiences of Australian jurisdictions and relevant international contexts. This report offered five quite profound conclusions that confirm earlier studies on this subject:

- "Overall, most people in this study said their disability support was better now than before they used individual funding. No people with disabilities who were interviewed reported that their current support arrangements were worse than their previous arrangements." (p27)
- "Individual funding has not increased the total specialist disability support cost to government. Officials said some individual funding is more cost-effective than other models of organising support, particularly where it supplements social housing and informal care." (p52)
- "Most people [in individualised funding contexts] were happy with their social relationships and community participation. Service providers attributed this to the whole-of-life approach

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[10] Note that the important goal of increasing the effective purchasing power of consumers can be achieved in ways other than via personalised funding packages. ATI supports the arguments framed by the Australian Federation of Disability Organisations (AFDO) in relation to the need for an appropriate Disability Inclusion Allowance as part of the income-support component of disability policy.
[11] This is especially the case within the aged care sector, but has also been the most common option adopted within state government disability funding agencies.

they can take providing support for people with disabilities who have individual funding compared to disability support clients who have other arrangements." (p58)

- "People with disabilities and their families also commented on how changing to individual funding had improved the wellbeing of family members because they could share the responsibilities." (p58) and

- "All respondents said that individual funding had improved their control, choice, independence and self-determination of their lives." (p58)

That is, the report concluded that the *provision of individualised funding improved the outcomes for individuals and their families and did so without increasing costs to government agencies*. This is a powerful and timely endorsement of the need for a significant shift in our approach to care.

The 'push-back' in response to the individualised funding movement has included the notion that regional and remote parts of Australia cannot sustain the required mix of supports unless funding is aggregated in traditional block-funding to designated service providers. ATI rejects this response. Tasmania is the least urbanised state in the Commonwealth (i.e., with the largest proportion of population living outside the capital city). It is a state essentially comprised of small towns. However, those small towns have frequently demonstrated that they can respond creatively and sensitively to new challenges. On the basis of Tasmania's (still fledgling) experience of individualised funding, Advocacy Tasmania is confident that new markets, new choices and new opportunities will emerge in response to the purchasing power of individually-funded individuals with disabilities.

ATI has direct experience of the difference that individualised funding can make for consumers. We have been active in supporting individuals in their struggles – typically over lengthy time periods – to justify to funding agencies that their needs cannot be met by existing block-funded service providers. The transformation for these consumers, once given real decision-making control over their care, has been dramatic. We acknowledge once again that individualised funding approaches will not be appropriate in all cases and indeed will not be sought by all consumers who are offered the choice. Where it is the preference of the consumer, however, and where appropriate supports can be provided to the consumer-as-purchaser and/or consumer-as-decision-maker, the option should be available as a default. The primary constraint on the proliferation of individualised funding approaches is no longer bureaucratic resistance[12] – it is resourcing levels. The transformation from a system built around block-funding approaches to one dominated by individualised funding requires the injection of 'bulge funding' to cover the transitional stage where parallel systems operate. The funding model for Australia's proposed care system must take these transitional costs into account.

> **Recommendation: Develop a suite of service options based around the concept of individualised funding to consumers as a means of maximising consumer choice and decision-making control.**

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[12] ATI is partnering with the Tasmanian Department of Health and Human Services in the organising of a symposium (in November this year) to further explore the ways in which individualised funding models can be expanded within Tasmania's disability sector.

E. MANAGING THE TRANSITIONS: THE ROLE OF ADVOCACY INFRASTRUCTURE

While there appears to be little disagreement with the notion that independent, professional advocacy services[13] are an indispensable component of a comprehensive care system, there is often confusion as to just where advocacy fits within that system. This confusion is apparent in the (valuable) diagrammatic schema offered in the Issues Paper (Figure 2, p15). Within this schema, there are a number of possible ways of framing the advocacy role. It can be seen as a service element in its own right, as part of the social infrastructure, or even as a contributor to the governance of the system (especially via the contributions to performance measurement, consultation and dispute resolution).

Advocacy Tasmania contends that the appropriate way to frame the role of advocacy is as an *essential infrastructural layer in the overall service system*. We see the advocacy process as a mechanism for maximising the (rights oriented) outcomes for consumers and for the continuous learning efforts of services and systems alike.

These roles are nowhere more important than within a system undergoing major transformation. The existence of independent, professional and accessible advocacy services for Australians with a disability is an important piece in the jigsaw puzzle of system reform. Advocacy Tasmania is acutely aware of the roles that we already play in supporting important change processes within Tasmania's services system. We are confident that the development of a national advocacy infrastructure will be an essential component of the change-management strategies required as we move towards a comprehensive, integrated care system.

Those change-management approaches will be required at three key levels: within the individual consumer's own trajectory of care; within the quality-improvement and service-development initiatives of service providing organisations; and at state and federal system level. Each of these levels is discussed below.

1. Supporting transitions in the consumer 'journey'

In Section D we discussed the four main phases of the consumer experience – or 'journey' – and the ways in which consumers are typically subject to substitute decision making rather than being engaged in taking their own decisions. Supporting Australians with disabilities to negotiate this trajectory – from initial access, through assessment and planning, to the specification of actual service delivery and participation in organisational-learning mechanisms – is a key role for advocacy services.

A second aspect of this consumer journey involves decisions to move from one service provider to another, or indeed from one service system to another (as when people move interstate). Irrespective of whether these decisions are made by the consumer or by another party, the transitions can frequently be challenging, even traumatic, for the individual and their family members. An efficient care service system must find ways of managing these transitions, and the

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[13] Importantly complemented by family and volunteer advocacy initiatives.

presence of advocates can maximise the decision-making capacity of consumers during these difficult processes.

Third, the transition to individualised funding – from being a passive recipient of services to an active purchaser of services – will offer its own set of challenges. ATI contends that this all-important system transition will require a comprehensive array of supports to consumers. These will include independent sources of advice about options and support when considering issues such as financial management, industrial relations, and equipment procurement. Centrally, though, consumers making the transition to a more central decision-making role in their own care will need advocacy support – typically in the early stages of the consumer deciding about the transition itself (i.e., whether to pursue/accept personalised funding) and the initial planning of the process.

2. Supporting transitions at service level

Advocacy services have a proven record of assisting service providers to better understand the consumer experience and to respond with changes to their models and their management approaches. The contribution made by advocacy organisations can be understood at two levels:

a. Service-level quality improvement

Two basic mechanisms apply here. First, advocates support consumers to communicate their needs and goals to service providers, assisting those service providers to understand the changes that may be required. Second, most advocacy organisations engage in forms of systemic advocacy, where emerging patterns within the consumer experiences are noted and communicated to service providers (or to funding agencies where appropriate). Members also regularly respond to service- or system-initiated requests for input to review processes and participate in formal complaints processes.

b. Cross-sectoral accreditation issues

At an accelerating rate, service providers are seeking external accreditation from quality assurance agencies. Some are doing this proactively, recognising that they will benefit from the range of processes associated with accreditation. Others are responding to pressure from funding agencies. The ability of accrediting bodies to monitor the views of the consumers of services is sometimes hampered by the capacity limitations of those consumers. Advocacy organisations have a key role to play in supporting consumer involvement in quality audits and this role will become more important as more organisations pursue accreditation. Appropriately-resourced advocacy organisations are also well placed to act as informants in their own right within these audit processes, having an independent perspective on the operation of the service-providing organisations.

3. Supporting transitions in the structure of Australia's care system

In Section E1 above, we noted the role of advocacy organisations in supporting consumers through difficult, often-traumatic changes to their care. It is likely that any major transformation of Australia's care system – especially one that compels service providing organisations to respond to

the direct purchasing choices of consumers – will result in significant levels of dislocation. Some service providers will grow and develop new service models; others will fail and disappear.

Without support to consumers and carers affected by these system changes, there will be pressure to maintain the status quo – the 'devil we know' – as a means of minimising the potential negative impacts. A comprehensive advocacy system, understood as a necessary infrastructural component of the emerging service system, will help to lubricate the wheels of change – change that is essential if we are to develop a care system that combines important human rights with allocative efficiencies.

> **Recommendation: Recognise that an important component of the change-management strategy required for Australia's care system is the further development of an infrastructural layer of independent, professional and accessible advocacy services.**

REFERENCES

ABS – Australian Bureau of Statistics, 2006, *People with a need for assistance*, Cat 4445.0, Canberra.

AIHW – Australian Institute of Health and Welfare, 2003, *Disability Prevalence and Trends*, Canberra.

AIHW – Australian Institute of Health and Welfare, 2009, *Disability in Australia: Multiple Disability and Need for Assistance*, Canberra.

CfOA IP – Productivity Commission Inquiry *Caring for Older Australians* Issues Paper, April 2010.

Fisher, K et al, 2010, *Effectiveness of individual funding approaches for disability support*, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Occasional Paper #29, Canberra.

HM Government, 2010, *Building the National Care Service*, Secretary of State for Health, London. (http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_114923.pdf)

National Aged Care Alliance, 2009, *Leading the Way: Our Vision for Support and Care of Older Australians*, Canberra (http://www.naca.asn.au/Publications/NACA_Vision.pdf).

United Nations, 2007, *Convention on the Rights of Persons with Disabilities and Optional Protocol*, New York (http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf)

Social Inclusion Board, 2010, *Activating Citizenship: A Social Inclusion Approach to Disability in South Australia*, Government of South Australia, Adelaide http://www.socialinclusion.sa.gov.au/files/Activating%20Citizenship%20-%20Social%20Inclusion%20Board%20-%20July%202010.pdf

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