Submission to the Productivity Commission inquiry into disability care and support

In Control Australia

August 2010

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Introduction to In Control Australia

About In Control Australia

In Control Australia is a collaboration involving a number of individuals and agencies around 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 those family members involved in their lives.

In Control Australia shares the *In Control* name with a number of international stakeholders, most notably *In Control England*. However, this does not mean in any way that *In Control Australia* is a franchise for a particular methodology operating in the UK.

The common use of the name signals a shared interest in the rights of people living with disability or other types of vulnerability, and the importance of such people being at the centre of the decision-making about their lives, and the importance of supporting people into valued roles as citizens within communities that value diversity. The common use of the name signals a common interest in discovering and sharing best practice, on an 'open source' basis.

There are many methodologies that will seek to uphold and advance people's right to make decisions about their personal supports, and to uphold and advance people's right to be active members of their local communities. In Control Australia is not wedded to one particular methodology, and will continue to discover and promote any elements that uphold and advance the notion of self-direction in people's lives.

To do this, In Control Australia focuses on five main activities:

1) ***Reference, information and awareness***
   People with disability having control of their lives is not a new or radical approach to disability support. In Control Australia has reference material on the range of tools used to support and ensure people with disability have control in their lives, as well as research documents showing how this approach has made a real impact for people. We are a repository of information and collect the real life stories of people in Australia who are in control and can show that this approach works.

2) ***Critical enquiry and reflection***
   It is not easy for government, service providers, or even people with disability and their families, to let go of the current systems which have an over emphasis on risk aversion, professional intervention and detailed accountability. Even the best services or policies which allow self-management for people with disability can fall back into old systems or do things better. In Control Australia is a place where people can ask critical questions of our service systems and reflect on where and why these systems may not be allowing people with disability and their families to have control of their lives.

3) ***Dialogue and exchange***
   There are many ways in which people with disability can be supported to self-manage and these are improving and changing. In Control Australia is a place where

information can be exchanged and discussion happen on the diversity of ways people can self-manage and be supported to stay in control.

4) ***Collaboration***
Systemic policy change involves many groups from different areas working together. In Control Australia believes that developing partnerships and collaboration allows for greater understanding and sharing of knowledge between diverse groups. A cultural shift towards people with disability self-managing must bring families, service providers, and funding bodies along.

5) ***Leadership and influence***
In Control Australia will lead the discussion on self-management for people with disability and raise it on to the agenda of government, service providers and advocacy groups. Those who are leading the way in practice now must be given the opportunity and space to tell their stories. In Control Australia is a place where these leaders can be fostered.

For further information about In Control Australia, please contact:

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In Control NSW has met regularly since 2008, and is comprised currently of the following individuals, representing the organisations for which they work:

Belinda Epstein-Frisch (Family Advocacy)

Carol Berry (NSW Council on Intellectual Disability NSW CID)

Michael Bleasdale (People with Disability Australia Inc, PWD)

Nicola Hayhoe and Garth Bennyworth (Ability Options Ltd)

Dan Cullane (Ability Options Ltd)

Christine Regan (NSW Council of Social Services NCOSS)

Professor Patricia O’Brien (Centre for Disability Studies, CDS)

Michaela Kennedy (The Sunnyfield Association)

Mark Clayton (The Sunnyfield Association)

Jordana Goodman (Physical Disability Council NSW, PDCNSW)

Damien Anderson (People with Disability Australia Inc, PWD)

Damian Griffis (First Peoples Disability Network Australia and the NSW Aboriginal Disability Network)

In Control Australia is led by Robbi Williams (Julia Farr Association), and Mark Pattison (National Council of Intellectual Disability, NCID). All the above individuals participated in the writing of this document.

How this submission was written (methodology)

The submission has been written collaboratively by the members of In Control NSW, together with the principal members of In Control Australia, Mark Pattison (NCID) and Robbi Williams (Julia Farr Association). It has drawn on the expertise within the In Control group, in various aspects of progressive support delivery, and their understanding of how individualised funding mechanisms operate successfully in international jurisdictions. The submission presents a literature review, which attempts to summarise the latest and most pertinent research and data related to individualised funding, with a view to asserting its effectiveness as a mechanism for providing the resources that people with disability require to meet their needs, and to assist them to live fully participating and inclusive lives in the community. Throughout the submission evidence from reports, evaluations and other documents is presented to back up our assertion that a new system should be delivered through individually funded means, because this is proven to work more effectively than the current block-funded system. All secondary sources are properly referenced, so that the wealth of material that exists on the success of individualised funding, properly and objectively evaluated in a host of other jurisdictions, can be accepted as evidence that this must be the way forward in Australia.

The submission also benefits from original contributions from In Control members, based on their experience and areas of expertise. The In Control group consists of people with disability, representatives of peak organisations, advocacy providers (including those who provide assistance to the families of people with disability) and service providers, and so has the capacity to view the issues that are raised in the development of a new disability support scheme from a wide range of perspectives.

The submission has benefitted from some original work, commissioned by PWD, by Steve Dowson. Steve Dowson, together with Brian Salisbury (Canada), has been at the forefront of the international movement to implement individualised funding to access supports for people with disability, and brings with him a wealth of evidence and experience of how it has been successfully implemented in international jurisdictions, and what problems and issues have been encountered. His original work, therefore, whilst focused on how a new system should operate in Australia, contains within it extremely contemporary analysis of how individualised funding is faring in other countries, which may currently be undergoing significant resource shortages due to the global financial crisis. His work is suitably acknowledged throughout, and previous work by Steve, and jointly with Brian Salisbury is contained in the literature review, and separately referenced at the end of this document.

The submission is also informed by In Control Australia's association with the In Control group in the UK, which has successfully implemented individual budgets and self-directed supports for people with intellectual disability. The In Control group has been particularly successfully in making available to people with intellectual disability and their families the rights and benefits of the Direct Payments Act 1996, by developing tools by which local authorities, who fund support arrangements, can readily determine levels of need and deliver the required resources.

In Control NSW has also undertaken some research, primarily in relation to the governance structure that we believe should take responsibility for all aspects of the new scheme. Whilst the section that deals with governance issues (see Part Two: Section 4) is derived in part from work that emerged from the workshop organised by the Australian Human Rights Commission (AHRC), the Australian Federation of Disability Organisations (AFDO) and People with Disability Australia (PWD) on 12 and 13 July 2010, along with original work completed under commission to PWD by Steve Dowson, it is further enhanced by the results of direct research (interview and report analysis) with Community Living British Columbia. Thanks are due to the cooperation of Doug Woollard (Vice-President, Organizational Development) and Brian Salisbury (Director, Strategic Planning) of Community Living British Columbia.

How this submission should be read (details of structure)

This submission aims to provide strong evidence for the new scheme to implement support to people with disability, utilising individualised funding, and other mechanisms that will guarantee that the person who receives support is in control of that support, and of the daily events that the support enables the person to participate in. To this end it provides a broad overview of how such a scheme might look from the point of view of a person with disability, followed by examples of how individualised funding and self-directed support arrangements have succeeded in significantly enhancing the lives of people with disability here in Australia. The overview section also provides an analytical framework for understanding how support arrangements works, specifically from the point of view of who is in charge of each of the processes. The diagrams presented in this part of the submission aim to clearly indicate how individualised funding and self-directed supports meet the requirements for self determination that are both explicit and implicit in the United Nations Convention on the Rights of Persons with Disabilities CRPD.

The submission is divided into two distinct parts: the first explains in some detail why In Control Australia believes that a new disability care and support system in Australia must be delivered by way of funds which are targeted at individuals with disability, and how that might occur, with reference to a range of individualised funding and self-directed support mechanisms which have been in operation in overseas, and in some Australian, jurisdictions for many years. This section includes a literature review, whose purpose is to provide the evidence that justifies looking seriously at implementing the new system through mechanisms which fund individuals, and which require services to deliver person-centred supports for which they will be remunerated directly by the person in receipt of those supports. This review also provides evidence that, in those jurisdictions which have facilitated individualised funding and self-directed supports, the benefits for those who have taken it up have been significant, and that risks have been effectively managed through appropriate safeguards for people with disability, and also for government funding bodies

The second part of the submission addresses the major points raised by the Productivity Commission in its Issues Paper, released 17 May 2010. It does this by adopting the framework of the five key questions raised in the Issues Paper:

1. What should be the focus of a new scheme?
2. What should a new scheme cover?
3. How much funding? Who decides this?
4. How should the scheme be governed? By whom?
5. Where does the proposed scheme fit with other government responsibilities to support the full inclusion of people with disabilities?

The information provided in this second section often references the information in the first part, and here this occurs we have inserted a hyperlink, so that the reader can quickly re-read this information.

The submission has been informed by a wider collaboration of the disability sector in Australia.

Part One: In Control Australia's Vision for the new disability care and support scheme : Principles and Practice

1: Key Principles for disability support schemes

1.1. 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

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

1.3. In Control believes that 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.

1.4. 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.

1.5. 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.

1.6. There must be additional provision, in the form of third party agencies, that can be used to provide higher levels of monitoring and protection to individuals who are at risk of harm or exploitation. As these provisions may impact on the individual's self-determination and privacy, they must only be used when, and to the extent that, they can be justified.

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

1.8. 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.

1.9. 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.

1.10. 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.

1.11. 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.

1.12. 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.

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

2. Principles governing supports

In Control Australia believes that a new scheme, and any disability system, should implement all supports that are required by people with disability who are eligible, by means of individualised funding, and that the new scheme should be shaped by principles that reflect best-practice in individualised funding. The following principle need to be in place:

2.1. A Fair Go

People living with disability should access the same opportunities as other Australians for a good life, including decent housing, a decent education, the opportunity to work, good healthcare, enough money to live on, and to be visible, active and valued at the core of our communities.

There are many aspects to a good life that we are likely to share a common interest in, and there will be other aspects a good life that are more unique to each of us based on our individually.

2.2. Front-Foot Investment

Disability support funding is there to assist the person to move towards a good life, characterised by the ordinary valued opportunities available to all Australians. Given that the funding comes from our taxes, which are an investment in the common good, it is important that public funds are used to support people towards that sense of good. It is not there to maintain a lifestyle of passive service recipiency. Key to this is that funds are allocated proactively, so that people are able to get on the front-foot in their lives.

2.3. Control

It is important the person has genuine control over how to spend their allocation of disability support funding, to choose arrangements that will feel right to him her/him.

2.4. Capacity

It is important to assume every person has capacity to make choices about how s/he would like to be supported towards a good life. People are usually the experts on their own circumstances.

2.5. Having an ordinary, valued personal vision

Any mechanism for disability support funding needs to ensure that there are resources available to assist a person envisage a good life for her/himself. This is particularly important to people who may have experienced years of passive service recipiency and whose personal horizons of what is possible may have diminished compared to non-disabled people.

2.6. Flexibility

Each of us on an individual journey through life. It therefore follows that if a person is receiving funding assistance, there needs to be full flexibility in how the funding can be spent.

2.7. Community Connectedness

Any mechanism for disability support funding needs to ensure that there are resources available to assist a person navigate into community life, and that a mechanism to meet the support needs is matched by government action to ensure that the wider community grows in its capacity to be welcoming and inclusive.

2.8. Accessible

All aspects of the funding mechanism are designed to be accessible and easy to use.

2.9. Ownership

The scheme’s beneficiaries should be extensively represented in the formal governance arrangements, so that the design, delivery and direction of the scheme are accountable to, and influenced by, the beneficiaries.

2: Literature Review

Introduction

This review pulls together some of the key themes from current literature and evidence within Australia and Internationally on how to meet the long term care and support needs of people with disability. It focuses upon four major themes:

1) What is understood by the terms “individualised funding”, “self-directed supports”, and other terms used to disrobe support arrangements which operate when resources are targeted directly to the individual who requires support

2) How individualised funding and self-directed support arrangements are and can be implemented

3) The quality of support and service delivery that has been evidenced from studies into individualised funding and self-directed supports

4) The costs and benefits of individualised funding and self-directed support, especially in comparison to traditional, block-funded service delivery.

The introduction (and signing up to, by the Australian Government) of the United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol (2006) marks a shift in thinking about disability from a social welfare concern to a human rights issue. (Chenoweth and Clements 2009: 5). This necessitates a review of the structures and mechanisms to achieve the objective of the convention that effect citizenship and inclusion for people with a lived experience of disability. International policy and practice, particularly in the United States, Canada, Scandinavia and the UK have moved to a citizenship/inclusive approach based on effected self-directed funding mechanisms.

Self-directed funding approaches are seen as key mechanisms for reforming and ensuring effective citizenship and self-determining engagement and opportunities for people with a lived experience of disability (Dowson and Salisbury 1999, 2001; Bleasdale 2001a and 2001b; Williams 2007)

Whilst the disability movement is characterised by difference and diversity, a significant point of convergence has been the demand for resources that are targeted toward assisting people with disability, to be placed under their control, so that the support that is delivered is unique for that individual, and achieves the goals that the individual has set for him/herself. The Seattle Declaration of 2000 was negotiated and agreed by delegates of a conference which had significant representation from members of the disability movement internationally, and sets out 35 principles of value and practical implementation of individualised funding. These principles are listed in Appendix 1.

Internationally self-directed options have been in play over the last 20 to 30 years. The assumption behind the need for effective disability supports, and the current criticism of the way that disability supports have been implemented (in the majority) to date, is that they have not facilitated for people with disability the experiences and opportunities that other people in society take for granted. Three key values and principles are identified to apply to self-directed options and to inform future vision.

These include:

- **Personal authority** – represents the notion of and the ability to make choices affecting one and is contrary to passive compliance. The UK organisation *In Control* refers to this as ‘independent living’. The assumption being that people “recognise their decisions have consequences and are content to live with these consequences” (Williams 2008: 10).
- **Interdependence** – recognises that communities need to be inclusive of all their members including people living with a disability (Ibid, 2008).
- **Capacity building** – recognises that throughout our life cycle we continue to learn and grow and hence any framework for self-directed funding must have capacity building embedded into every encounter.

These values need to underpin and to be expressed by any organisation that supports and provides services and supports to people with disability. The extent to which people with disability are supported to participate in the crafting and shaping of this vision will determine its success. All structural arrangements should reflect these key values.

1. Understanding what is meant by Self-Directed Support, Individualised Funding and mechanisms for effecting inclusion

1.1. Definitions

“Individualised funding” is a term is currently used to describe different funding mechanisms that target resources to an individual – in this case a person with disability – in order for that person to receive the support that (s)he needs. In the hands of departmental officials, it encompasses a range of options, with the principal focus being upon the “unit-costing”/or bands of support and resources around that individual’s needs, such that contractual arrangements with specialist service providers focus upon addressing that individual’s needs. However, amongst people with disability, and their allies and associates, it has a very distinct emphasis, which is that the funding for support is placed under the control of the person requiring support. In this way the person who is the consumer of the support becomes also the customer (or employer) of the support, and acquires the power and choice that is generally associated with a service purchaser or employer. In this way it is often associated with the term “self-determination”, which of course refers to the level of autonomy, choice, decision-making and empowerment that the person with disability enjoys, as a result of having such options available.

Individualised funding is, essentially, a technical option, a mechanism of funding, that is geared toward people with disability achieving self-determination. It has been in operation in a number of guises since the 1970s, but the movement for its more widespread adoption as a service system mechanism which should be available to all people with disability (indeed to all people who are in receipt of some sort of social support or care) gathered momentum in the 1990s. Below is a widely accepted definition of individualised funding:

> "… funding that is allocated to the individual based on his/her unique strengths and needs, and placed under the control of the individual to enable them to live in the community as a full citizen". (Dowson and Salisbury, 1999)

This definition is supported through other bodies of work (Stainton 2005; Fischer, Gleeson, Edwards, Purcal, Sitek, Dinning, Laragy and D'Aegher 2010; Williams 2007). Individualised funding as a mechanism aims to address fundamental issues of self- determination and control, and is, in the main, characterised by the following elements:

- Funding is directly allocated to an individual, not to a specialist disability service;
- Funding is portable – it moves with the individual, and also moves to where the individual prefers to spend that money;
- It facilitates control over how monies are spent to meet support needs.
- The amount of funding is determined by direct reference to the individual and their specific needs and aspirations, in either an independent or a family context;
- The individual, either independently, or with assistance from family or other supporters determine how funds are used;
- It will provide for the support necessary to meet disability related needs and to assist individuals to be/become contributing citizens; and
- Individualised funding makes a positive contribution to community inclusion options.

Contemporary (2010) Australian research commissioned by the Australian Government, distinguishes between the terms 'individualised funding' and 'individual funding' and adopts 'individual funding' for reasons of plain English (Fisher et al, 2010: 7). It is worth noting, however, that the term they used also includes the possibility of individually allocated funds being paid directly to service providers, which differs qualitatively from the definitions outlined above, and provides a point of difference between the terms "individualised funding" and "individual funding". Their definitions form part of their report which examined the effectiveness of approaches to individual funding of disability support. This report describes individual funding as a defined package of funding allocated for spending on disability support services of a given person in the way which best suits them, including the disability support type and who provides the support. This contrasts with block funding whereby governments or contracted service providers are funded to provide a defined disability support type to a defined number of people or as many people as they can (Ibid).

> …individual funding is a way of organising consumer directed care that has been introduced into most Western European countries and parts of North America. In the United Kingdom (UK) individual funding is generally referred to as 'direct payments', in the United States of America (US) as 'self-determination', in Canada as 'self-managed', and in some European countries as 'cash for care' (Fischer, et al, 2010: 7).

Self-Directed Supports. As discussed above, individualised funding is a mechanism by which it is widely asserted that people with disability may successfully direct and remain in control of the supports that they require in their everyday lives. One of its consequences, therefore, is the delivery of "self-directed supports".

Family Advocacy NSW have written about these self-directed supports:

> A self directed approach is underpinned by the values of independence, choice and social inclusion and is designed to enable people to direct their own services and supports rather than attempting to fit within pre-existing service systems.
> Core elements of a self directed approach include:

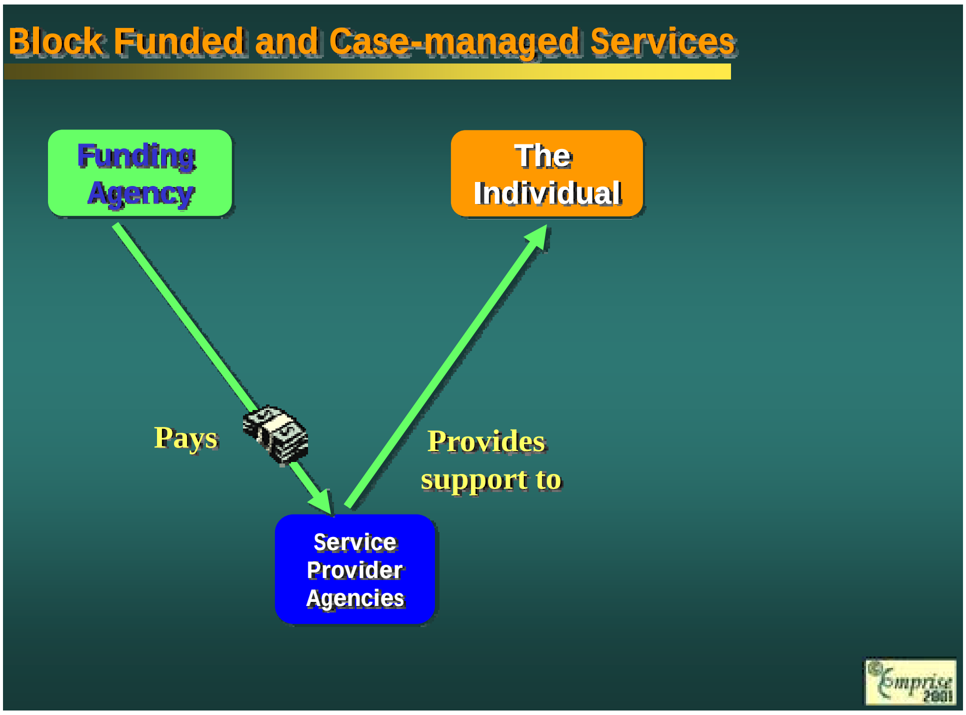
- self directed planning: planning that is personalised and directed by the person and their family/support network or in the case of children, is family centred;
- self directed funding: funding that allocates resources to the individual and their family/support network early in the process to enable the design and identification of supports that are flexible and responsive to individual needs;
- self directed support: support in which a combination of formal and informal, public and privately provided services and supports are coordinated to deliver the best outcomes in response to the individual's circumstance (Family Advocacy 2010).

All of these definitions clearly indicate that the most important feature of individualised funding and self-directed supports is the element of control that the person with disability, or those authorised to work on their behalf, has over the funds that are allocated to her or him. These in turn are used to purchase supports that are truly tailored to the individual's needs, thus providing a much stronger basis for effectiveness, and, eventually, value for money.

1.2. Block-funded systems

Disability services have previously been, and remain predominantly, block-funded. In most jurisdictions control over resources hence power and control resides with the funder and provider. Providers contractually and implicitly recognise that structurally it is the funder they are accountable to and whom they must satisfy in order to maintain funding. This places limitations on the capacity of individuals and their significant others person to both a right of exit and contractual status (Stainton 2005: 2).

Dowson and Salisbury (2000) have previously clearly delineated between arrangements which are individually funded, and those which are block-funded:



Block Funded and Case-managed Services

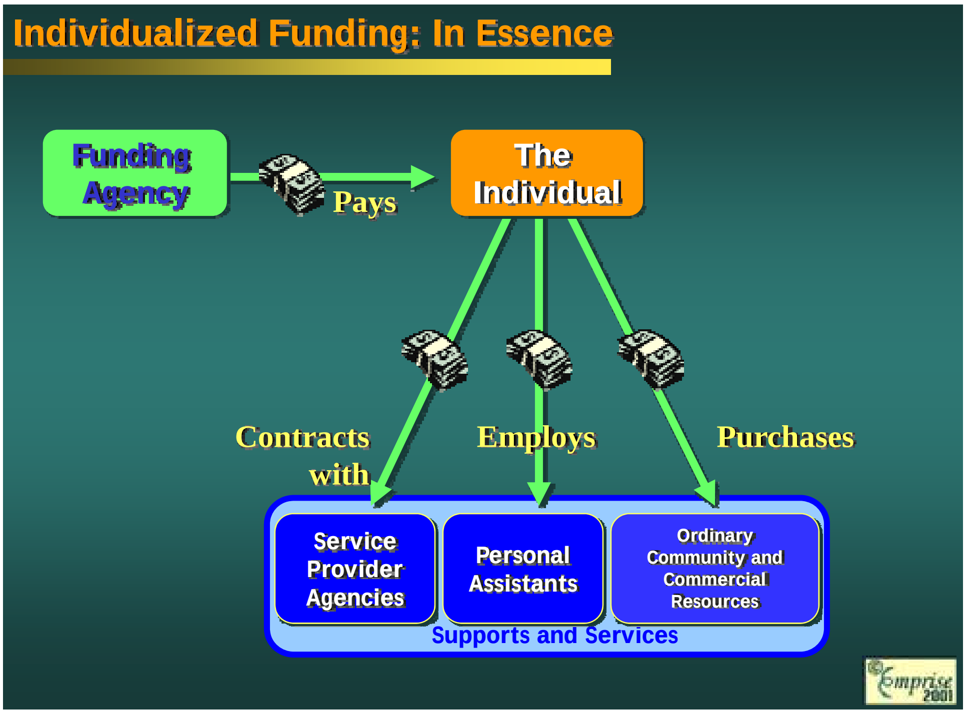
Funding Agency

The Individual

Pays

Provides support to

Service Provider Agencies



Individualized Funding: In Essence

Funding Agency

Pays

The Individual

Contracts with

Employs

Purchases

Service Provider Agencies

Personal Assistants

Ordinary Community and Commercial Resources

Supports and Services

At this level individualised funding is a fairly straightforward mechanism, which is designed as simply as possible to transfer control over the running of supports to the person with disability themselves. This requires purchased supports to be accountable directly to that person if continuity of service provision is to be maintained.

In the Australian context, Bleasdale (2001a) has made the distinction between “individualised packages”, such as those delivered by the 300 Places program in NSW in the mid 1990s, and truly individualised funding arrangements. The contractual relationship between the funding body and the individual is of key importance, something that was missing from the 300 Places program:

> The 300 Supported Places Project in fact represented the targeting of funds to individuals, whilst utilising the existing block-funded system. Contractual arrangements were between the government department and the service provider, not between the department and the individual (Bleasdale 2001a, 14).

The dominant approach to individual funding in Australia is still an individual funding package held by a service provider (Fisher et al 2010). The exceptions are Western Australia, which has a longer history of the use of direct funding and a direct payment pilot has been completed in Victoria and in NSW is available through the attendant care program. Individual funding in Australia should facilitate direct control and choice in support provision.

2. How Individualised Funding is implemented

2.1. International initiatives, policies and legislation

Individualised funding (IF) as a mechanism to support choice and control by people with disabilities has been in use in various forms since the 1970s, and with growing application since the 1990's. In general initiatives have come from movements of people with disability, and of the families and carers of people with disability, with responses from government departments eventually translating into policy that first allows, then facilitates both individualized funding and the delivery of self-directed supports. In the UK, legislation sets out the right of people who receive social care services to receive funding for supports instead, providing a number of criteria are satisfied.

In North America, particularly Canada, a much longer history of IF exists than in the UK. Virtually every province has some variation of individualised funding underway, particularly in support of people with intellectual or physical disability. Bleasdale (2001a) has outlined how in 1976 in British Columbia a group of families lobbied successfully for the deinstitutionalization of their children, and for the use of the funds to establish completely independent and unique support arrangements – and in the process coined the term "brokerage". In Alberta individual funding has been in place since the mid-1980's, and since 1990 has become the key funding mechanism (Williams, 2007). Nova Scotia introduced the Self-Managed Support-care Act in 2005 which makes provision for funding to be paid directly to people with disability to purchase their own support (Williams 2007)

In 2002 in the United States, some form of individual funding was in place in nearly three quarters of the 43 states surveyed and is becoming a mainstream funding mechanism. (Chenoweth. et al, 2009; Williams, 2007).

In England, Direct Payments legislation in 1996 instituted payments directly from the local authority to individuals to purchase their own supports. A broader version of individualised funding, allowing the funds to be managed by a range of third party agents, is now a central element of government policy to implement personalised social care. (Glasby and Duffy, 2007 in Williams, 2007). The In Control UK group, and the various systems tools that it has devised, was born from the difficulty that people with intellectual disability and other cognitive impairment had in satisfying local authorities that they were both willing and able to manage their own supports, and to properly acquit the funding they received.

The New Zealand Government in 2005 began contracting a disability organisation to provide an IF service. There administrative arrangement allows some people living with disability to hold, manage or govern their own needs assessed disability support budgets (Litmus Ltd, 2007 cited in Chenoweth, et al, 2009: 9).

2.2. Resource allocation/Personalised Budgets

Individualised funding is seen as an effective mechanism by which to encourage user-led, self-directed supports, as it provides resources directly to where the demand is, rather than to the supply chain (disability-specific services). In those jurisdictions where individualised funding has been provided as a total package of resources to people with disability who require support, the role of the individual budget has been pivotal the delivery of supports, and to the quality of the outcomes that have been produced.

Stancliffe and Lakin (2005) have studied the result of implementation of individual budgets amongst those people with disability for whom support dollars have been provided, and looked at whether or not this has increased or enhanced levels of self-determination, which they identify as being "disturbingly low" in traditional services in community settings (p.204). Their research found that there was no strong correlation between a person's disability and their likelihood of utilising individualised funding mechanisms, thus the comparisons they drew with people using traditional services were valid. More independent, home settings were generally accessed by people using individualised funds, however, greater evidence of self-determination was found when other, more proactive strategies (eg person centred planning, brokerage etc.) were used to support the individual budget (Head and Conroy (2005).

Individual budgets feature prominently in the methodology used by In Control in the UK, whose model has been adopted by many local authorities to enable people with intellectual disability to access direct funding to purchase supports. The Islington Council in London describes individual budgets (referred to below as IBs) as:

> ... the money you get to pay for your support and other things in your support plan. Your IB can be spent in a way that suits you, as long as it's legal and doesn't put you at risk. It must meet your needs and goals as written down in your support plan, and agreed with your care manager.
> You can get your IB as a direct cash payment to pay for your own support. You can also choose and arrange your own support but let us or a third party look after the money – this is called a 'virtual IB' .You can also have a combination of both.
> Your IB can include other funding that you get towards your support such as the Independent Living Fund (Islington Council undated)

There are a range of approaches that enable a change of focus from the service to a person centred perspective. These include:

> ***Direct Payments:*** are a system whereby people with disabilities have the required funds to purchase supports paid to them, and the choice is mainly theirs as to which providers they use and which types of support they have access to. The money is paid directly to them to purchase supports and they remain responsible for location, employment, management, accounting In some programs in the USA and the United Kingdom, preloaded debit cards, also known as smart card, are given to individuals to use to purchase services in line with the planned budget (Bleasdale, 2001b; Clements, 2008).
>
> ***Cash and Counselling*:** Although models vary, the essence of these programs are that *Cash and Counselling* gives consumers a monthly allowance that they may use to hire workers, and to purchase care-related services and goods (Brown, Carlson, Dale, Foster, Phillips & Schore, 2007).

***Indirect Payment via Intermediary – Host Agencies*:** Some people who require support may, for various reasons, prefer to receive their services from agencies funded by block grants, and, although it would be contrary to the values on which IF is based to deny them their choice, these arrangements technically equate to more traditional, block-funded arrangements, with accountability being between the service provider and the funding body (Dowson & Salisbury, 1999). In British Columbia, however, Community Living British Columbia (CLBC), which administers the disability support system, makes individualized payment to what are known as "host agencies", who handle the funds on behalf of, and for the benefit of, the individual. These host agencies will also manage aspects of the support, including employment, training of staff etc, but will not be the agency that delivers the support.

Alekson (2010) has reported that a budgeted approach was adopted initially in England, the Netherlands, and the United States, and maintains a more direct connection between a participant's needs and the goods and services purchased to meet those needs. This follows a three-step process. First, an individual budget is calculated for an eligible person, indicating how much is available to spend in a year on home and community-based long-term care services. An individual budget may be set in one of three ways: 1) it may be based on the cost of services that would otherwise be authorized for an individual if he or she chose services delivered by a home care agency, 2) it may be based on the cost of services used by an individual in the previous year, or 3) it may be based on a predictive model that matches an individual's needs to a budget amount. In 2004 for example, Germany launched a planned budget demonstration, and since seen a shift towards planned budgets, even going so far as legislating the model (Alakeson 2010).

2.3. Support Arrangements

There is a generally accepted view that the implementation of individualised funds leads to support arrangements which are truly unique to the person with disability – therefore, talking about "models" of support is superfluous. However, in those jurisdictions where individualised funding has been implemented for some time, and where the funds are targeted to meet a person's holistic needs, a distinct pattern of support begins to emerge.

2.3.1*. Direct employment of personal assistants*. This model is favoured very much by the movement of people with disability. Barnes and Mercer (2006) point to the emergence of the Centre for Independent Living in Berkeley in 1972, and the development of user-led, user-controlled supports which later became known as the "Independent Living Movement". In the UK, the introduction of direct payments has led to many people with disability choosing to employ their own assistants direct, to provide support with personal care, assistance with housework and shopping, "and other forms of practical help to participate in social and leisure activities (Barnes and Mercer 2006, 95). This arrangement can be organised by means of direct payments, or by means of an individual budget which is managed by a financial intermediary.

2.3.2. *Microboards*. These emerged in British Columbia in the 1980s, and are now in operation across Canada, in various States in the USA, in Ireland and other countries of Europe, and in Western Australia (Vela Microboards 2010). Essentially, microboards combine elements of circles of support with formal structures (that of a non-government organisation) around an individual with disability, in such a way as it forms an intentional and supportive group for friendship and advice, which also has the capacity to be used as a means to channel funds for specialist supports (Bleasdale 2001b). Again, the support that is eventually delivered to the person with disability is uniquely tailored to her/his needs and wishes, and decisions and choices are informed and supported by members of the microboard. This form of support has been used successfully with people who have significant levels of impairment, and, whilst families feature prominently in many microboards, they have also been used to successfully support people who have no actively participating family members. The microboard constitutes a non-profit society comprising of a small group of committed family and friends formed around a person with particular needs for support (National Council on Disability, 2005). The group addresses the person's planning and support needs to ensure maximum control by the person for whom it is created. Some jurisdictions have created microboard associations to assist families. These associations provide development, support, and training (Chenoweth and Clements 2009, 14).

2.3.3*. Person-Centred Planning.*

Dowson and Salisbury (1999) have pointed out that in traditional disability service systems planning has always been a function of the services themselves, and that, to an extent, this can represent a conflict of interest, either framing individual needs in such a way as to "fit" the existing service vacancy, or shaping an individual preference to accord with the options and choices that the service can provide. They identify that much debate has occurred, alongside that of individualised funding and having greater individual support, about the fact that planning, ideally, should take place outside the framework of the formal service system.

O'Brien and Lovett (2000) have detailed how person-centred plans, developed outside of the service framework, can lead to outcomes that are often hard to envisage within a service context. Their emphasis is not so much upon the negative influence of services, and the possibility of conflicts of interest, but more upon the need to focus from the beginning on issues of connectedness with the community, which leads in turn to the development of goals, and the means to reach those goals, which are first and foremost embedded in the community. Thus, some people with intellectual disability, whose difference poses a challenge to service providers (which can lead to restrictive practices), can have their ambitions and needs met in a community, rather than a specialist disability, context.

Kretzmann and McKnight (1993) have long advocated for a much more direct relationships between people who are marginalised, such as people with disability, and their community, without the mediation of specialist services. They contend that the removal of people from community settings and into specialist settings fails to meet basic needs for dignity, companionship and hope for the future, and that the community is also deprived of its richness if it continues to hide it diverse populations. They see detailed person-centred plans as the tools by which the gifts and talents of people with disability can be identified, and strategies developed that will tap these skills, ultimately to the benefit of the community.

Garner and Dietz (1996) highlight the process of person-centred planning, which is usually supported by family members and friends, operating as a circle of support. In this regard, the process of developing a plan is an important outcome in itself, as the relationships are clarified, and, importantly, decision-making on the part of the "focus person" (the person with disability) is aimed for at all times. O'Brien and Lovatt also emphasise the importance of the process, and how it acknowledges and brings to the fore, the strengths of the person with disability, so that these strengths are the first that are utilised in achieving goals, and supports and services are brought in to complement and enhance these strengths. Duffy and Sanderson (2004) have also identified how person-centred principles can be implemented in a more traditional social care environment, but one which places the individual choices of the person with disability at the fore.

While planning with and for individuals may be most energetic, creative, and person-centred when it takes place outside the formal service sphere, there is a real danger that it will not lead to action by the formal services, and so fail to stimulate change. An individualised funding system can correct this weakness by ensuring that the person-centred plan is translated into a set of requirements for the types of service required, and the characteristics of the services that providers will be expected to deliver. In turn this means that service providers, while not the right people to define the life goals of a person they support, will need to learn to operate in ways that are person-centred. In short, 'person-centredness' is not just a method of planning, but an approach to people with disability that needs to permeate the whole system.

2.3.4. *Brokerage.* As identified earlier, this is a specialised term, which is derived from the generic term "honest broker", which is understood as a "person or party that is considered to be neutral and able to mediate between two parties" (Wiktionary). The role of the broker in assisting people with disability to access the supports they require, in ways that suit them and those around them, has been in development since the devolution of the Woodlands institution in British Columbia back in the 1970s. Schouten (2001) has provided a detailed account of the various tasks which a broker undertook, to source and shape service provider responses that would meet the needs of her daughter with disability, and the circumstances of her family. This account highlights three important aspects of a broker's work:

- expertise and understanding of what resources might be available to assist a person with disability who requires support to live their lives in the community, and how to source and obtain these resources;
- absolute commitment to the interests of the person with disability, and those around them;
- ability to find solutions to the various happenings and occurrences of life, that will inevitably interrupt a neat, linear plan, and reorientate the person to adapt to new challenges and circumstances.

A broker in that instance was hired specifically to overcome significant challenges, and involved engaging an independent specialist, who was in no way connected to either service providers or the funding department. "Brokerage", as a discreet element of individualised service assistance, is gaining acceptance as a legitimate item of expenditure, that will ensure planned supports are correctly configured and delivered. In the UK Councils are required to put in place 'enabling frameworks' that include brokerage to provide assistance with planning and setting up of supports. (Dowson & Grieg, 2009: 24). Four broad strategies are identified that can be used to generate sources of brokerage help:

- Skills training and development support to increase skills in planning and brokerage.
- Information resources provided that informs as they make their own plans.
- Existing works assisted to extend their competencies to include guidance in planning and brokerage.
- The workforce is augmented with people whose specific role is assisting people through the planning brokerage process.

The last item on this list corresponds to a person acting as a support broker ion the kind of specialised, technical planning role originally envisaged by the families in British Columbia.

The UK National Development Team for Inclusion's (NDTI), recommendations emphasise the support broker as someone who works as a contractor. Brokers should be selected by the customer and deliver their service according to terms specified by the customer, the contract ending when work is completed to the customer's satisfaction. Services should be task focussed, efficient and honest. Brokerage roles should cover all stages of the planning process up to implementation, but not extend to secondary support services after implementation. (Dowson & Grieg 2009, 24). In the UK context, no clear policy has yet emerged regarding the method by which brokers should be paid. In Control (England) advocated that people should pay for any brokerage services from their individual budget allocation. However, English councils have mostly commissioned agencies to provide brokerage services from salaried staff, with no charge to recipients. There have been one or two pilot projects that have tried alternative systems, such as voucher systems to pay accredited freelance brokers (Dowson 2007, 12).

Dowson and Grieg (2009) maintain that brokers should be free of loyalties – notably with the local authority or support providers – which could weaken an independent ability to work in their clients' interest. Brokers need to be trained to a level where they offer reliable advice to help people decide between obtaining support by contract or employment (Dowson & Grieg 2009, 25-27). Being a broker, requires a diverse range of competencies across an identified range of tasks, a contractual relationship that is customer-focused, and a regulatory context to provide safeguards. (Dowson 2007, 3). People choosing to use these services should be able to access brokers with reasonable confidence that they will have at least a basic level of skills and knowledge, will work ethically, and will be genuinely independent. The NDT put forward the following three characteristics as a means of assessing this (NDT website, 1).

1) **Absolute:** There are some areas – notably those concerned with values and basic inter-personal skills – which people must meet to work as a broker, and for which evidence should be available by the end of the training course. Evidence from training that a participant does not meet these requirements is likely to result in a recommendation (to the training commissioner and/or accrediting body) that the person should not be accredited.

2) **Subject to confirmation:** Some competencies, particularly the more technical skills, may not be demonstrated directly during the course, though the person's previous life experience or work may indicate these. Where there is no negative evidence, but a lack of both direct and indirect supportive evidence, a recommendation of accreditation may be made, subject to the condition that further evidence is acquired from monitoring the person's early practice as a broker, and that there is both the opportunity for further learning and a commitment by the broker to achieve the learning that is necessary. The scope to make a recommendation of this sort is much greater if there are strong and reliable arrangements to support and monitor brokers after training.

3) **Continuing development:** Developing the specific skills required for the role of broker, and gathering knowledge about services and community resources, must be a continuing process. A high level of competence in these areas is not required for accreditation, provided that the person has the foundation of basic values and inter-personal skills, and a commitment to invest in their own development.

The delivery of key outcomes of personalisation requires people either have themselves or have access to the skills and knowledge required to plan and organise their supports. Brokerage is an aspect of personalisation that merits attention. Support brokers are intended to ensure participants receive information and assistance to make informed decisions regarding their budgets and to assist in monitoring the appropriate use of public funds. (Quach, O'Çonner and McGaffigan 2010, 30).

2.3.5. *The self-directed service model (UK)* In 2003 the ***In Control*** partnership (UK) was established as the self-directed model for people with learning disabilities with six local authorities. By November 2007, the model spread from people with learning and physical disabilities to older people who make up most of those receiving social care; 107 local authorities were members of *in Control* and 2 300 people (mostly elderly) were receiving personal budgets (Leadbeater et al 2008, 21-23). ***In Control*** provides a range of information and supports to people with a disability and families about self-directed supports, individual budgets and new ways of delivering funded support through processes of critical enquiry, dialogue and collaboration (Chenoweth et al 2009, 15).

Characteristics of ***In Control*** working:

- **Resources are allocated up front:** People draw up a self-directed support plan which describes what matters most to them, what they wish to achieve and how their use of the budget will enact these changes. It should be noted that, "a support plan is not a wish list. Each plan must specify how it will meet government policy objectives to keep a person healthy, safe and be signed off by a local authority care manager." (Leadbeater et al, 2008: 24).

- **Plans are adaptable:** People are encouraged to adapt their plans as they learn what works best or if their circumstances change. Adaptable budgets for example are more effective for progressive conditions.

- **People are active participants:** They shape their goals for the services they use and ensure the money is well spent.

- **Self-directed services are simpler to administer and more cost effective:** One reason being that users are incentivised to source cheaper alternatives. In the most expensive cases savings are reported as substantial - up to 45% (Leadbeater et al, 2008 40).

2.4. Self-Directed Support in Australia

Within Australia there is growing policy interest in individual funding and to cautiously implement self-directed approaches. The move across all jurisdictions is to allocate funding to an individual; that is portable; how the resources are spent is defined by an individual and their families or circle of support within the parameter of policy guidelines and by program; and is held by a service provider.

However, there is a continuum of individual funding approaches are in place across jurisdictions, with varying levels of choice and control, portability, capacity to individualise and accountability. A strength of an individual funding approach is its potential to provide individuals with the opportunity to access a wider range of support, including a mix of specialist, general, informal support options and supports that are relationship based (Fischer et al, 2010). There also continues to be a dominance of access to services by program rather than an approach that operates across a person's life span.

Three elements to the approach in Victoria include:

- portable support packages based on an individual plan attached to the person;
- funds held by a service provider or a financial intermediary;
- Or direct payment (under development).

Victoria has adopted the language of 'self-directed approach', rather than 'individual funding', as they believe it provides a stronger basis for personal control and remove the focus from the finances. The three components of the approach are self-directed planning, support and funding. People are supported to access non-traditional, non-centre based activities. Support and Choice is open to anyone with a disability in Victoria across the age spectrum. In the second option, the financial intermediary is the bill payer and is responsible for reporting and accounting to government and the person with disability for how funding is spent. However, decisions about how the money is spent rests with the person and their family (Ibid, 22).

Over the last year focus is on streamlining the range of programs offering individual funding into one cohesive program, Individualised Support Packages, with one set of guidelines. Victoria is developing a resource allocation tool to assist in the assessment process and funds allocation. The tool aims to facilitate access and equity within the individual funding approaches. In 2009 they focused on enhancing people's access to services locally and to build strengths within local communities. They are also unbundling support in day services, with the aim of increasing choice, control and portability (Ibid, 23).

Western Australia (WA) applies a range of individual funding approaches, with portable funds held by providers, facilitators and direct funding to individuals and families. Direct funding is facilitated through the Local Area Coordination (LAC) program, which has run for approximately 20 years. All WA funding is individualised, with the exception of some respite and therapy. WA refers to this as a 'notional allocation against each individual', not an individual package. The rationale behind individualising funding through a notional allocation is facilitating portability (Ibid, 23). Evaluations of LAC have identified that, most people and their families highly value direct payments. Direct payment provides a level of control to individuals and families, allows them determine who will provide support and when.

WA will explore new options for people wanting to set up self-directed options. Official priorities include streamlining financial and administrative systems, and a greater focus on outcomes and flexibility.

2.4.1. *Direct payment Options*

Direct payment options are available:

- In NSW through the Attendant Care program. A financial intermediary has been established to manage, payroll and insurance as an option to assist people;
- Victoria has a number of people in receipt of direct payments. A direct payment pilot was implemented in 2006-2007. The evaluation (LDC Group 2007) found higher consumer satisfaction and cost effectiveness because consumers were able to negotiate more support with the funding provided. Change in satisfaction related to greater levels of choice, flexibility and control (Ibid, 23).
- In Western Australia direct payments are made through the local area coordinators as noted above.

In Australia less than half of people living with disability (45%), and for whom individualised funding is available, hold the funds themselves. Funds were portable between agencies for 47% of people or between facilitators (17%). Only 33% could flexibly spend funds on multiple providers and in the open market for 25% of people with individual funding (Fischer et al 2010: 8). Services providers continue to hold the funding (80%). However all respondents in the study said that individual funding had improved their choice, control, independence and self-determination in their lives.

Queensland currently has a range of funding models. Legislation in Qld specifies that resources can only be provided to incorporated non-government organisations. If a person receives funding they must incorporate as an organisation and meet the requirements of a service provider.

Direct funding options has been identified as working well in rural and remote areas where there are limited service providers and local solutions and options can be developed (Ibid, 19).

3. Service Quality

This section will review literature that has as its focus the quality of supports that is necessary to enable people with disability to have their needs met, to participate and be active citizens. This is evaluated from the individual perspective and sense of satisfaction across a range of quality of life domains.

3.1. *Self-directed supports contribute to enhanced quality of life*

Australian and international studies identify that participants of direct funding report improved outcomes in across all quality of life domains (Fischer et al 2008; Williams 2007, pp. 18-20). A draw back identified is the time responsibility. This again suggests that appropriate supports to facilitate self-directed options needs to be available in the form of secondary or third supports. The expansion of individual funding and self-directed option was supported, with a caution to not overburden with administrative requirements.

The literature indicates that control, choice, independence and self-determination are drivers to other quality of life indicators (Williams 2007). The findings from the literature include:

- **Health and wellbeing**

People with disabilities and their families who receive individual funding report a similar or higher level of personal wellbeing compared to the rest of Australia’s population. Using a standard measure of wellbeing, scores on all domains (standard of living, achievement in life, personal relationships, personal safety, and community connectedness) are similar or higher than the scores for the broader Australian population, except for personal health and future. The scores of people using individual funding are higher than normative data for Victorians with intellectual disabilities in the domains of personal health, achievement in life and personal safety, but lower in personal relationships, community connectedness and future security (Fisher et al 2010, 53).

- **Satisfaction with Physical and Mental Health**

All direct funding participants noted decreased levels of stress. Reasons include not having to deal with inflexible service providers and less conflict with the attendant carers and providers; better attendant carers and quality of care, control of OH&S management; and direct management of attendant carers concerns about pay, conditions and relationships between the attendant carer and the provider. Participants are less likely to use agency attendant carers so the quality of care is higher on average. Positive changes for direct funding participants included regular meals and attendant care support for medical procedures (Fisher et al 2008, 6-8).

- **Confidence and self-esteem**

All participants expressed a feeling of empowerment and self-reliance, knowing that full control and management is in their own hands, therefore they have a vested interest in getting things right.

- **Family relationships**

Funding participants report higher than average satisfaction with their personal relationships and improved family relationships more flexibility to make social arrangements with family and friends (Fisher et al 2008, 9-11).

- **Community and social participation**

Higher than average satisfaction with community participation is reported, including those with significant physical support needs, with over two-thirds indicating very high or high levels of satisfaction with time spent with family and friends (Fisher et al 2010, 56). Flexibility in employment arrangements in direct funding has also assisted them to travel for work, study, holidays and to visit family in other regions of the state (Fisher et al 2008, 11-12).

- **Economic participation**

All participants surveyed are in paid employment, study or active retirement. At least half the participants increased their roles and work capacity since accessing direct funding and are mostly in paid employment. Few spoke of financial constraints affecting participation, yet did speak about the cost of disability, for example, purchasing equipment and problems accessing PADP because they are working (Ibid, 13). People with intellectual disabilities participating in a paid employment and training program, for example, were without exception very happy with their economic participation. People using attendant care were happy with the extent to which their support could be used to get them to and from work (Fisher et al 2010, 57).

- **Impact of Individualised Funding on People with Intellectual Disability**

Available evidence indicates that individualised funding has provided more opportunities for people with an intellectual disability (Fyson & Kitson 2007; Social Care Institute for Excellence 2007).

DEMOS, a UK based 'think tank' advocate that self-directed services are an approach which, "delivers highly personalised lasting solutions to people's needs for social care, education and health at lower cost than traditional, inflexible and top down approaches." (Leadbeater et al 2008: 9)

DEMOS identifies that self-directed services deliver huge payoffs:

- People get personalised solutions giving them a better quality of life.
- They facilitate greater societal participation at lower costs than traditional service solutions, which often isolate and leave the beneficiaries feeling dependant.
- Participative approaches put the individual in charge, and "at the centre of the action." (Ibid, 11)

- Personal budgets enable people to get the kinds of services they want and to be more social, where as traditional public services that often cut people off from society. Hence they are better for individuals and society.

DEMOS describe the transformation enabled by this process having five main ingredients (Ibid, 11-12):

- It changes people's attitudes towards themselves and their role in the service: they become less isolated, depressed, dependant and rather more optimistic energetic and confident.
- People's relationship with professionals change: service professionals guide people to make better choices for themselves and give a greater and more direct voice to beneficiaries (users).
- Self-directed services introduce new and diverse knowledge and information which helps shape services.
- The supply side of service provision adjusts to user demand and represents a challenge for local authorities and private sector service providers.
- A shift in power occurs from service providers to service users with greater responsibility accorded to users.

Tim Stainton of the University of British Columbia makes the point that, to date, there is limited research evidence on individual funding and that which is available is often limited by its transferability to other jurisdictions due to variations in context or approach. Various approaches to individual funding have emerged over the last 25 years as individual funding has gradually become part of the disability and to a lesser extent the disability policy landscape in many worldwide jurisdictions (Stainton, 2005: 1). There is evidence, however, from people with physical disability, those with an intellectual disability and dual diagnosis, and their families, that self-directed funding enhances control over their own lives and effectiveness of support. Individual funding as a policy mechanism has become embedded in a discourse of rights, freedom and equality within the disability communities - as a emancipator mechanism. Stainton suggests that through exploring the commonalities of experience across the jurisdictions, primarily Canada, the US and to a lesser extent the UK and Australia to highlight some of the common issues and challenges, one can identify what is common to individual funding implementation and what general approaches may be effective across these (Ibid, 2008: 1-3).

In the USA a number if "self-determination" projects were run in the 1990s, which enabled people with intellectual disability, and their families, to access individual budgets, and to purchase the supports they believed they needed to address their needs and improve their quality of life. Head and Conroy (2005) have conducted an analysis of the results of the Michigan Self-Determination project, testing the outcomes against a straightforward hypothesis:

1. If people gain control,

2. Their lives will improve, and
3. Costs will not increase (Head and Conroy 2005, 220)

Their study involved analysing data against a range of instruments, including the Personal Life Quality protocol (PLQ), and the Decision Control Inventory (DCI), as well as other more qualitative and subjective measures and techniques. The study found significant increases (over the course of three years) in control over life decisions, especially in the areas of hiring and firing support staff, choice of agency support person, choice of whom to live with, choice of house or apartment, and choice of case manager, traditionally areas where people with disability who receive services have experienced least choice and most frustration (Head and Conroy 2005, 229-231). In terms of their quality of life the findings were that this had also improved markedly, especially in terms of individual happiness, and the ability for people to get out and about. In terms of costs, the study found that costs had decreased over the course of 3 years by 16%, largely because the support needs of people had decreased from what they were at the start.

Evaluations such as this, and others done of the Self-Determination project, are rigorous in their approach, and unequivocal in the results that they report. On virtually all scales the means and ends of the self-determination approaches outscore those delivered in controlled, segregated, staffed disability services.

3.2. *Addressing the potential risks*

With the introduction of a new system of operating disability supports, there are , understandably, concerns raised about a number of things, not least the potential for failure of supports when managed by people other than service providers; and the risk to the service provider organisations, who will become reliant upon the satisfaction of service recipients to remain viable. These concerns have been raised and addressed in thos jurisdictions where individualised funding and self-directed supports have been implemented, and the success of those arrangements evaluated against these risks. The following lists some of the finding in this regard:

- **Accountability:** the international experience identifies that there is a high level of accountability in self-directed funding and the use of resources in line with the funded support plan. In the UK local area authorities engage in ‘light touch’ monitoring and auditing systems to maintain accountability. Activities of commission charging brokers who advise service receivers should be monitored and licensing them is a consideration. (Leadbeater et al 2008, 45).

- **Transition:** Many challenges are associated with the transition from the current system and for a model to be effective it must be embedded in a system which supports its use and is predicated on enhancing the rights and self-determination of a family or individual. Introducing self-directed funding without any support mechanisms around planning, implementation and the fiscal aspects of managing one’s own supports can add to the challenges faced by families or exclude those not in a position to undertake these roles. Governments need to ensure management and implementation supports are in place (Stainton 2008, 9-10).

- **Support plans**: Support plans are crucial to facilitating budgetary objectives, yet without resources to support this are ineffective. Investing in well trained people to support budget holders to develop their support plan is a key to ensuring self-directed services are successful (Leadbeater et al 2008, 51).

- **Effective Risk Management:** Traditional services can be risk averse when devising a plan for someone. This restricts creative ways of organising support. However, self-directed services engage people in managing risks associated with their support and draws on detailed knowledge of capacities of family or friends.

- **Equity:** Misconceptions exist in the UK that the traditional system treats people in a fair and consistent way thus ensuring equity and equality. Leadbeater et al, identify in the DEMOS report that a poor fit exists between what people need and the type of resources spent on them. This results from the way in which local authorities buy blocks of provision. Consequently people with different needs receive different services, the current system rewarding the most articulate at the expense of the less confident. More personalised funding mechanisms are good for opening access to services for minority ethnic groups. In Oldham (UK) minority groups constitute 22 percent of the population yet 1 percent of people accessing social services yet a move to personal budgets increased this figure to 10 percent (ibid, 47-48).

- **Rural / urban:** Widespread dissatisfaction exists with the current UK traditional services system and 90 percent of the population live in urban centres. Take up of personal budgets in rural areas has seen service receivers devise creative localised solutions (Ibid, 49-50).

- **Measuring outcomes**: Innovation cannot be sustained unless its value can be proven. The shift to self-directed services will require new ways of assessing local authority performance and form a step towards measuring the performance of social care standards across local authorities. This new measurement system would need to be outcomes based rather than outputs driven.

- **Growing the model**: Self-directed services are a potential model for developing personalised solutions at a lower cost while gaining increased value for money. Although self-directed services are not applicable to every setting, for example national defence, other sectors for personalised budgets include (Ibid, 67-77):

  - maternity services
  - job search and employment
  - drug user & offender rehabilitation
  - young people not in education, employment or training
  - mental health
  - supporting families at risk (for example the Western Australian Local area coordinators)

- aged care.

The International literature identifies that self-directed support has given individuals access to a wider range of service providers and options, such as critical counselling and therapy services, education and vocational opportunities, aids and equipment's, computers, gym membership. (Alakeson 2010, 6; Glendinning et al. 2008 cited by Alakeson 2010, 3).

The UK's Individual Budgets pilot programme found that deciding how to use an individual budget was challenging for some. Support planning, while being judged as person focussed and accessible, drew concerns over the amount and complexity of paperwork and slowness of the support planning processes.

3.3. *Training issues*

The United Kingdom's (UK's) *Individual Budgets* (IB's) programme identified that training and supervision in implementing the new IB approach were seen as essential. Social care staff sometimes felt that their skills were being eroded (Ibsen, 2008).

Other workforce issues include staff training. Many people are not too concerned about qualification but may require support staff to have certain specific training such as seizure management or safe lifting. An emerging issue in some jurisdictions is serious support staff shortage. This is usually related to pay levels so funders need to ensure that IF allocations allow for realistic salary levels within the persons area. Staff cover for emergencies or unexpected contingencies can be problematic. Back-ups can be required and an option is for the government or support agency to contract with a care agency to provide short notice care for IF users (Stainton 2008, 11).

A 2009 study (FPLD 2009, 10-11), by the UK based Foundation for People with Learning Disabilities (FPLD) identified that the most effective training for person centred planning was that which

- Included managers of services so they gain understanding of how their staff need to work and how planning can be led by individuals and their families.
- Included families and other day to day support providers
- Was based on real situations
- Adopted an eclectic approach to tools and techniques

4. Cost and Value for Money

International evidence indicates that where individualised funding has been used over a longer period of time that there has been no greater cost than through other funding mechanism such as block funding. This is consistent regardless of the size of the package (Stainton 2005, 7-8).

Stainton, refers to a 2002 study in the United States that found varying results. Yet it identified that in three states including:

- New Hampshire there was a 12.4%-15.5% cost reduction;
- Michigan the cost reduced by 6.7% on average with the greatest reduction amongst those with the highest (and costliest) needs;
- California where the cost rose for both the self-determining and control groups but cost rose at a rate 50% less for the self-determining group and the study concludes that IF is a very effective break on cost escalation.

In the UK little difference was found between the average cost of an individual budget and costs of conventional social care support (Chenoweth et al 2009, 5; (Leadbeater 2008, 37; 2008 Ibsen study on the UK Individual Budgets). In Australia, individual funding has not increased the total specialist disability support cost. In fact it has been identified as being more cost effective with individuals gaining greater value for money from the resources (Fischer et al 2010; Leadbeater 2008, 37). In a pilot study in Arkansas, it was found that groups who chose to direct their own services obtained 100 hours of personal care instead of only 70 per hours compared to the control group (Schore and Phillips 2004 cited by Alakeson 2010, 4).

One phenomenon which appears to be unique to direct payment arrangements of individualised funding is that of actually returning funds to the funding authority. Bleasdale (2001b) reports that this is relatively common, certainly more common than is the case of service providers returning unspent funds to the funding department, and quotes a personal correspondence with a man in Canada who utilises a direct payment arrangement:

> When I first started getting [Individualised Funding Project] funds the program was just a pilot. The first year I had a surplus of over $5000. The second year was even more. The majority of other people I talked to were reporting similar numbers. I would hazard a guess that it was only the users who were inadequately funded in the first place who had any money problems. On the other hand, if the funds went to an agency, they were always completely spent with no questions asked. It was a given that the agencies had overhead and the Province had no problem paying their fees (Jones 2000).

Head and Conroy (2005) have reported that it is common amongst the Self-Determination project, where people have individual budgets, for the amounts used to decrease year by year. This is largely due to the high level of need decreasing after the first year, which in turn may be due to the increased levels of ability and confidence that are demonstrated by the individual in the operation of their support arrangements, and the control they have over their life choices. This has also been identified by Alakeson (2010) in the Netherlands and the UK. He also identified that in the UK long care services purchased through self-direction cost between 20 to 40% less than the equivalent services provided by local government (Hasle, 2003 cited by Alakeson 2010). Those in receipt of self-direction payment are good stewards of public monies.

Although cost seems to have risen in the Arkansas example of SDC, the researchers attributed this to participants utilising their full personal care entitlements unlike those who were not on SDC. It was also suggested by the researchers that although personal care expenses had risen, nursing home use reduced by 18 per cent (Benjamin and Fennell 2007 cited by Alakeson 2010, 4). Rigorous control group studies were conducted on the Cash and Counselling (CC) initiative in Arkansas by an independent research body. The Arkansas project shows CC in the first year was more expensive than traditional methods but the authors note that the level of service was far higher in the control group. Despite this difference by year two the cost had reached relative neutrality. The authors conclude adopting a "Cash and Counselling" model of consumer direction can be a cost-effective way to substantially improve the access to care and well-being of people eligible for Medicaid personal care.' (Stainton 2008,7-8).

Similarly, in the example of Florida, it was seen that participants of SDC were significantly less likely to use crisis stabilisation and crisis support compared with non participants. This was mainly attributed to SDC clients being able to engage in more preventative focussed services. Early intervention as Alakeson argues, tends to improve outcomes; allowing individuals more hours in the community than in inpatient settings. These outcomes are positive because crisis services are the most costly inpatient services costing between $500 to $650 per day (Alakeson 2010, 7). As such, it was found that SDC had the potential to increase the value of health care dollars by improving the effectiveness of care and implementing preventative measures (Alakeson 2010).

The various data and reports indicate that there is a significant, positive cost-benefit relationship between individualised funding, individual budgets, self-directed supports, and positive outcomes for people with disability in terms of their quality of life and decision-making capacity. There would appear to be, however, a stronger correlation of positive effects if a person's total package of support resources becomes available to them to expend on well-identified needs and goals. This means that piecemeal approaches to "individualising" pockets of formal service provision, such as infrequently accessed respite, or recreation programs, will not have the same impact as would have total control of all resources. The ultimate goal of individualised funding and self-directed supports are to qualitatively change the way that supports are delivered to people with disability, so that the service does not become an end in itself, but rather the means to an end, the end determined by the person with disability. As Moseley, Gettings and Cooper (2005) conclude:

> ... a successful transition cannot be achieved through incremental adjustments in the status quo but rather require focused attention to fundamentally alter all aspects of program delivery (2005, 287).

Bibliography

Alakeson, V. (2007). Putting Patients in Control: The case for extending self-direction into the NHS, Social Market Foundation, London.

Alakeson, V. (2010). *Issues in International Health Policy International Developments in Self-Directed Care,* U.S. Department of Health and Human Services, 78, February.
Arksey, H. Fernandez, J. Glendinning, C. Jones, K. Knapp, M. Moran, N. Netten, A. (2007). *Individual Budgets Evaluation: A summary of Early Findings.* Individual Budgets Evaluation Network: United Kingdom.

Arksey, H. Challis, D,. Fernandez, J. Glendinning, C. Jones, K. Knapp, M. Moran, N. Netten, A. (2008). *The national evaluation of the Individual Budgets pilot program.*. Individual Budgets Evaluation Network: United Kingdom.

Arksey, H. Glendinning, C. Harris, J. Jacobs, S., Jones, K. Marthorpe, J. Moran, N. Netten, A. Rabiee, P. Stevens, M. Wilberforce, M. (2009). *Individual Budget: Impacts and outcomes for carers.* Individual Budgets Evaluation Network: United Kingdom

Askheim, OP. (2005). *Personal assistance—direct payments or alternative public service. Does it matter for the promotion of user control?* Disability & Society, 20(3).

Barnes, C. and Mercer, G, (2006), *Independent Futures: Creating user-led disability services in a disability disabling society*, The Policy Press, Bristol.

Bigby, C. Fyffe, C. & Mansell, J. (2006). *Roundtable on Intellectual Disability Policy*. (La Trobe University, Bundoora, Paper presented at the Roundtable on Intellectual Disability Policy, Institute of Advanced Study.

Bleasdale, M. (2001a), *Individualised Funding for People with Disabilities: The Scope for its Development in Tasmania*, State and Commonwealth Ministerial Briefing paper #2, Advocacy Tasmania, Speak Out Tasmania, and Citizen Advocacy, available [online], http://www.advocacytasmania.org.au/publications/individualised_funding_paper.pdf

Bleasdale, M. (2001b), Empowerment through Individualised Funding: Challenges for people with disabilities, service providers and governments, paper given at the "Sharing the Road" Conference, Griffith University, Brisbane 25 and 26 June 2001, available [online], http://www.members.shaw.ca/bsalisbury/Empowerment%20Through%20Individualized%20Funding%20-%20Michael%20Bleasdale.PDF

Brown, R., Carlson, B. L., Dale, S. Foster, L., Phillips, B., and Schore, J. (2007). *Cash and Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home- and Community-Based Services.* Princeton: Mathematica Policy Research Inc.

Chenoweth, L. & Clements, N. (2009). *Funding and service options for people with disabilities*, School of Human Services & Social Work, Griffith University.

Clements, L. (2008), Individual budgets and irrational exuberance, *Community Law Reports,* Vol. 11, 413-440.

Commission for Social Care Inspection (2004). Direct Payments. What are the barriers? Commission for Social Care Inspection, available [online], http://members.shaw.ca/bsalisbury/direct_payments.pdf

Community Living British Columbia (2005) *Transforming Community Living Services in British Columbia,* (Vancouver: CLBC)

Community Living British Columbia (2010), Policies and Procedures, Policy No. SE 4.240 – Host agency funding, available [online], http://www.communitylivingbc.ca/policies_and_publications/documents/HostAgencyFundingPolicy.pdf

Dowson, S. (1999), *Who Does What? The process of enabling people with learning difficulties to achieve what they need and want*, Values Into Action, London.

Dowson, S. (undated) *Independence and the support broker role*, (United Kingdom, National Development Team for Inclusion.

Dowson, S. (October 2007). *Independent support brokers: The why, what, and how*, United Kingdom, National Development Team for Inclusion.

Dowson, S and Grieg, R (2009). The emergence of the independent support broker role Journal of Integrated Care, 17, 4, 22-30

Dowson, S., and Salisbury, B., (1999). *Individualized Funding: Emerging Policy Issues,* Roeher Institute.

Dowson, S. and Salisbury, B. (2000). *The Seattle 2000 Declaration on Self-Determination and Individualized Funding,* [online] http://members.shaw.ca/bsalisbury/decfinal.rtf

Dowson, S. & Salisbury, B. (2001) *Foundations for Freedom: International Perspectives on Self-Determination and Individualized Funding,* Baltimore: TASH.

Duffy, S. and Sanderson, H. (2004), Person centred planning and care management, *Learning Disability Practice*, Vol. 7, No. 6, pp. 12-16.

Felce, D., Perry, J., Romeo, R., Robertson, J., Meek, A., Emerson, E. and Knapp, M. (2007). Outcomes and costs of community living: semi-independent living and fully staffed group homes, American Journal on Mental Retardation, 113, 2, 87-101.

Fernández, J-L., Kendall, J., Davey, V. and Knapp, M. (2007) Direct payments in England: factors linked to variations in local provision, Journal of Social Policy, 36, 1, 97-121.

Fischer K.. Gleeson, R. Edwards, R. Purcal, C. Sitek, T. Dinning, B. Laragy, C. D'Aegher, C. & Thompson, D. (2010). *Effectiveness of individual funding approaches for disability support: Occasional Paper no 29*, Disability Studies Research Centre, Social Policy Studies, University of NSW.

Fisher, K. & Campbell-McLean, Carolyn. (2008). *Attendant Care Program Direct Funding Pilot Evaluation,* Sydney, University of New South Wales.

Fyson, R. & Kitson, D. (2007). *Independence or protection - does it have to be a choice? Reflections on the abuse of people with learning disabilities in Cornwall*. Critical Social Policy, 27(3).

Garner, H. & Dietz, L. (1996), Person-Centred Planning: Maps and Paths to the Future, available [online], www.ttac.odu.edu/Articles/person.html.

Glendinning, C., Clarke, S., Hare, P., Maddison, J. and Newbronner, L. (2008). Progress and problems in developing outcomes-focused social care services for older people in England, *Health and Social Care in the Community*, 16, 1, 54-63.

Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K. and Tyrer, J. (2000b). Bridging the gap; using direct payments to purchase integrated care, *Health and Social Care in the Community*, 8, 3, 192-200.

Head, M. & Conroy, J. (2005), Outcomes of Self-Determination in Michigan, in R. Stancliffe and K.C. Lakin, (eds), *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, Paul H Brookes Publishing, Baltimore.

In Control UK (2010). A Brief History of In Control, available [online], http://www.in-control.org.uk/site/INCO/Templates/General.aspx?pageid=90&cc=GB

Islington Council (undated), Choice and Control: Your complete guide to Individual Budgets in Islington, available [online], http://www.in-control.org.uk/DocumentDownload.axd?documentresourceid=1163

Jones, R. (2000). Internet Posting, cited in Bleasdale, M. (2001b), Empowerment through Individualised Funding: Challenges for people with disabilities, service providers and governments, paper given at the "Sharing the Road" Conference, Griffith University, Brisbane 25 and 26 June 2001, available [online], http://www.members.shaw.ca/bsalisbury/Empowerment%20Through%20Individualized%20Funding%20-%20Michael%20Bleasdale.PDF

Kretzmann, J. & McKnight, J. (1993), *Building Communities from the Inside Out: A Patch towards Finding and Mobilizing a Community's Assets*, ACTA Publications, Chicago.

Lakin, K.C. & Stancliffe, R. (2005), Expenditures and Outcomes: Directions in Financing, Policy, and Research, in R. Stancliffe and K.C. Lakin, (eds), *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, Paul H Brookes Publishing, Baltimore.

Laragy, C. (2008). *Australian research on individualised funding for people with intellectual disability: new opportunities or unacceptable risks?* La Trobe University.

Leadbeater, C. Bartlett, J. & Gallagher. N. (2008). M*aking it Personal,* United Kingdom, Demos.

Leece, D. and Leece, J. (2006) Direct payments: creating a two-tiered system in social care?, *British Journal of Social Work*, 36, 8, 1379-93.

Mansell, J. (2006). *Deinstitutionalisation and community living: progress, problems and priorities*, Journal of Intellectual & Developmental Disability, 31(2).

Moseley, C., Gettings, R. & Cooper, R. (2005), Having it Your Way: A National Study of Individual Budgeting Practices within the States, in R. Stancliffe and K.C. Lakin, (eds), *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, Paul H Brookes Publishing, Baltimore.

NDT, (undated). *Independent support brokers: Required competencies and characteristics,* United Kingdom, National Development Team for Inclusion.

O'Brien, J. & Lovatt, H. (2000), Funding A Way Towards Everyday Lives: The Contribution of Person-centred planning, in J. O'Brien & C.L. O'Brien (eds.), *A Little Book about Person-Centred Planning*, Inclusion Press, Toronot.

Perry, L. (2000). *What is a Vela Microboard?* [Online]. http://www.microboard.org

Perspectives on Self-Determination and Individualized Funding. Baltimore: TASH.

Priestley, M., Jolly, D., Pearson, C., Riddell, S., Barnes, C. and Mercer, G. (2007). Direct payments and disabled people in the UK: supply, demand and devolution, British Journal of Social Work, 37, 7, 1189-1204.

Quach E.D., O'Conner D, McGaffigan E. (2010). Supporting People with Disabilities in Managing Individual Budgets, *Professional Case Management*, Volume 15 - Issue 1 - p 29–37

Riddell, S., Pearson, C., Jolly, D., Barnes, C., Priestley, M. and Mercer, G. (2005). The development of direct payments in the UK: implications for social justice, Social Policy and Society, 4, 1, 75-85.

Schouten, A. (2001), A Service Broker Can Make a Difference, *Common Sense*, Issues 8, pp. 11-16.

Stainton, T. (2005). *Empowerment and the architecture of rights based social policy*, Journal of Intellectual Disabilities Vol. 9, No.4.
[Online] http://jid.sagepub.com/citmgr?gca=spjld;9/4/289

Stancliffe, R & Lakin, K.C. (2005), Individual Budgets and Freedom from Staff Control, in R. Stancliffe and K.C. Lakin, (eds), *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, Paul H Brookes Publishing, Baltimore.

The Roeher Institute (1997). Evaluation of Self-Managed Direct Funding Pilot Project (Toronto: Centre for Independent Living Toronto).

The Roeher Institute (1999). Towards Inclusion: National Evaluation of Deinstitutionalization Initiatives, Toronto.

The Roeher Institute (2000). Evaluation of Individualized Quality of Life Project - Final Report Toronto.

Vela Microboards (2010). What is a Vela Microboard?, available [online], http://www.microboard.org/what_is_vela.htm

Wightman, C. Editor. (2009). *Connecting People, The steps to making it happen,* London, Foundation for People with Learning Disabilities.

Williams R, (2008). *Individualised Funding General Considerations on Implementation,* Julia Farr Association: Adelaide.

Williams R. (2007). *Individualised Funding a summary review of its nature and impact, and key elements for success,* Julia Farr Association: Adelaide.

APPENDIX 1 – The Seattle Declaration

THE SEATTLE 2000 DECLARATION ON SELF-DETERMINATION & INDIVIDUALIZED FUNDING

(This Declaration was developed during the First International Conference on Self-Determination and Individualized Funding, which was held in Seattle in July 2000, and was presented in draft form to the 1250 attendees at the closing plenary.)

This conference has been founded on the certainty that people with disabilities have the same rights as other citizens to freedom, equality, equal protection under the law, and control over their own lives. These rights must be honoured if people who have disabilities are to be fully included as valued citizens in the relationships and opportunities of community life.

Many people require personal supports or other services to ensure their full citizenship and inclusion. These supports and services must be funded and provided at a level and in ways that uphold the rights of the individual.

This conference is no less certain that these rights have often been disregarded. Citizens who have disabilities experience oppression in many aspects of their lives. The causes of oppression include poverty, other people's attitudes, and the systems of publicly and privately funded support services, comprising –

6) laws, policies and regulations;
7) state and private sector funding bodies;
8) agencies which provide services.

These systems operate in ways that deny control to those they are intended to serve. Without accountability to those who require their assistance, these systems decide how, where and with whom people shall live and spend their days. While this situation persists, people of many nations will not be able to exercise their rights or fully participate in their communities. For these reasons, this conference calls on policy makers in all countries, at all levels of government, and on agencies which provide support, to ensure that the assistance made available to all citizens is based on the following principles:

Self-determination: Founding principles

1 Self-determination for people with disabilities must be the founding principle of public policy.

2 Legislation to promote self-determination or individualized funding must be grounded in the principles of human rights and social justice.

3 Self-determination is a birthright which must be upheld by government. It is not a commodity to be delivered by services.

4 All people, including individuals with disabilities, have rights and responsibilities to live as full citizens. The barriers that stand in the way must be eliminated.

5 The development and implementation of policy must take account of the interdependence of the individual; others with disabilities; the community; and government.

6 Policy and practice must acknowledge and honor risk-taking as an essential element of self-determination and an important part of life.

7 Demands that individual self-determination should only be allowed when certain standards are met must be rejected.

8 The many contributions made by people with disabilities, which include innovation, problem-solving, improvements in accessibility, and other contributions to humanity, must be recognized.

Action required to support self-determination

9 People with disabilities speak from personal experience, and so with authority and expertise. Their views should be valued, and not regarded as having less importance than those of professionals.

10 People with disabilities and their families must be present and central at all planning and decision-making tables in policy development.

11 Citizens with disabilities and their supporting networks and organizations must be in charge of developing and promoting public policy which is related to the provision of supports.

12 Policy must be designed and implemented to ensure the inclusion of people who are at the risk of exclusion or disadvantage on the basis of

ethnicity, culture, gender, race, religion, sexual orientation or other grounds.

13 Negative, entrenched attitudes, both within and beyond services for citizens with disabilities, must be addressed.

14 An understanding of disability as a consequence of society's organisation and other people's attitudes (the 'social model') rather than the inevitable result of the individual's impairment (the 'medical model') must be promoted.

15 Other citizens must be encouraged and educated to recognize that people with disabilities are entitled to access, accommodation and supports; and that individualized funding is the best way to target supports that meet peoples' needs.

16 Governments must require that public funding is used to create systems which support self-determination. Such systems will be characterised by innovation, a focus on results, and employ people with disabilities and their families.

Individualized funding: Guiding principles

17 Individualized funding arrangements must allow for flexible practice within consistent guiding principles.

18 Individualized funding and planning systems must be flexible and responsive to the culture, values and preferences of each person and their family.

19 People must not be required to give up their right to acquire income and personal assets in order to access public funding for disability supports.

20 There must be universal access to funding and support, within a range of individual need which must be defined through a collaborative process.

21 Individual funding systems must include arrangements to provide assistance, where required, in the management of funding and supports, and not limit eligibility on the basis of judgements of 'capacity'.

22 The design of individualized funding systems must reflect the reasonable assumption that recipients are trustworthy.

23 Individualized funding must be recognized as a means to honor people's vision for the future.

24 Individualized funding must be recognized for its value as an investment in people and communities.

Individualized funding: Principles for implementation

25 The funding allocated to each person should be based on their individual need, not on pre-defined and arbitrary limits.

26 Individuals must be free to pay the providers of their choice, including family members.

27 Individuals must have full control over their supports, including the planning of supports, and choosing and directing their support providers.

28 People must have a choice of budgetary and administrative support services to assist them in using and tracking their individualized funding.

29 People must be given the opportunity and support to explore options and make their own choices of sources for forms of assistance such as brokerage, advocacy, and peer support.

30 Service providers and agencies must be encouraged to endorse and apply the principles of self-determination and individualized funding; and, in an expanded organizational role, to deliver supports that minimize dependency and strengthen partnerships with the larger community to address barriers to freedom and opportunity.

31 Individualized funding systems, support services, and technical assistance services must be designed and provided so as to ensure that their forms of communication, physical and environmental characteristics, and overall quality do not undermine their accessibility.

32 Individualized funding arrangements must be straightforward and easily understood by everyone.

33 Action must be taken to encourage the recruitment and employment of people with disabilities in the administration of individualized funding systems.

Individualized funding: Evaluation

34 When the success of Individualized Funding is assessed, the evaluation must take due account of the improvements in quality of life, and in particular the extent to which personal choice, control and sense of belonging are enhanced.

35 When proposed or implemented individualized funding systems are compared with block-funded services, it must be recognized that block-funded services have not been generally successful, either in terms of the efficient use of public funds, or in the quality of life provided to the people who received the services.

Seattle 2000 Declaration Website: http://members.home.net/directfunding

3: The Australian Disability Support Authority - Broad Overview

a) The Vision

The idea that supports to people with disability can be delivered in a way that truly enables them to live rich and active lives still appears to be a pipedream to many who work very closely in a daily basis with people with disability, let alone to the broader population. Below is an imaginary radio interview with a woman with physical disability, who is accessing support which is purchased through funding from the new Australian Disability Support Authority. The purpose of this vignette is to emphasise how incredibly ordinary and everyday are the aspirations of people with disability, and how these everyday aspirations can be facilitated by a subtle, but significant change in the way that we deliver the support, and the funding for that support, to enable people with disability to take control of their lives.

Extract from Radio National's *Life Matters* program, in 2017, with Gerry the presenter.

Gerry

Disability may be a minority issue, but it still affects a great many Australians – not only the estimated twenty to twenty-five percent of the population under retirement age who live with disability, but also their families and carers.   For the many citizens with disability who need additional help from government, the arrival of the Australian Disability Support Authority, ADSA, promised some big changes.   This month is the fifth anniversary of the launch of ADSA, so we're going to spend the last section of the programme today looking at whether ADSA has been a success.

With me are two people with their own, and very different, perspectives. Joanne took the role of National Director of ADSA from its outset, so she's the woman who's had to make the whole thing work. Miriam, on the other hand, is a leading national advocate and campaigner for citizens with disability, as well as being a person with disability herself, and a recipient of support from the Authority.

Joanne, maybe I could start with you. What exactly is ADSA?

Joanne

Hi, Gerry, and thanks. As the name suggests, ADSA is a national scheme that enables people with a disability to access the support they need to live a life with the same rights and opportunities as other citizens.

It's important to see ADSA as separate to the financial assistance – for instance Disability Support Pension - that's offered nationally through Centrelink. Many citizens with disability find themselves facing extra costs simply because they live in a world which isn't geared to their needs.   Some extra money through the Disability Support Pension and other allowances such as rent assistance and mobility allowance can offset those costs.

But some people face much higher costs – typically because they need substantial levels of support with living.   ADSA is there to help with those needs. This assistance is also available to people who may earn their income from paid work, but for whom the additional costs of living with disability need to be acknowledged and offset somehow.

Gerry

OK, but surely that kind of help isn't new? ADSA didn't invent accommodation support or day centres!

Joanne

Absolutely not! But there are two really important differences with the new system.   First of all, the fact that it's a national scheme means that people can have much more certainty about the help they'll get.   Previously, each state had its own rules about who could access help, the amount of help on offer, and even the kind of support services available. With ADSA, a person with disability who moves from one state to another should have the assurance that the level of assistance they get won't change.

The second big difference is that ADSA leaves people much more in control of their lives. I'm generalising here, of course – some states and programmes were showing the way ahead before ADSA started. But all too often the price for getting help was that the professionals took control – assessing people's needs, deciding what services people should receive. People got slotted into existing services, rather than having support designed to meet their individual requirements. With ADSA, people aren't told what services to use. Instead they get control of a pot of money, which they can spend to meet their support needs.

Gerry

So it's another form of cash payment, like the Disability Support Pension?

Joanne

Well, no, but it's getting closer to that. The fact is that people with disability used to be slotted into services, which were run or funded by governments, to provide them with the supports they needed to get by each day. I, personally, hope that we shall gradually move towards a single system where people with disability can get all the financial support they need through an entitlement-based scheme. What the ADSA gives us now, though, has moved us on considerably from the situation we had previously, when services were block-funded by governments, who could pick and choose, to some extent, who got support and what that support was.

So in practice nowadays it is more of a partnership between the government and the individual. The individual is provided with an amount of money – an ADSA budget – which is broadly in line with the level of their disability. However, the actual amount is agreed and handed over on the basis of a costed support plan that the person has drawn up and submitted.

Gerry

Costed support plan? Could you spell out what that means in practical terms?

Joanne

Sure. The ADSA system includes an assessment procedure that will check whether a person is eligible for a ADSA budget and also indicate roughly what size of budget would be available. There's even an online version of the form that will instantly calculate a figure. You can see it at the ADSA website. But – and this is really important! – the figure is only a guide, a ballpark. It's meant to be enough for the person to start figuring how they could use the money to get the support they need and improve the quality of their life. When they've decided on the best plan, it's written down as a short document called a Support Plan. The Plan then goes through to a meeting of ADSA decision-makers. The person has an absolute right to be present at this meeting, or to have independent representation, because in principle this meeting is concerned with finding the balance between the individual's requirements and the need to use public funds with care. In practice, though, these meetings are almost always very constructive – not the sort of heavy negotiation you might imagine. There's an honesty and openness that both sides value enormously.

Once a decision has been made, the ADSA budget is made available, and the plan is put into action. We do make some checks later on – but they're more about being sure that the plan has delivered what the person wanted rather than checking up on the fine details of how the money has been spent.

Gerry

OK, so that's the ADSA view of how it works. Does that match your experience, Miriam?

Miriam

Well, I do have some concerns, but on the whole I'd have to say that it's turning out to be very good – at least compared to the old system. And that's not just my experience as someone who relies on support. It's the overwhelming viewpoint I'm hearing.

In my case, moving across to an ADSA budget was quick and easy. The process didn't characterise me as a person who had a lot of needs and incapacities - instead it encouraged me to think about myself as a whole person – as someone who with the right to be respected both for my big dream, and for my silly habits and small preferences. I came onto the scheme three years ago, and on the first occasion I went to discuss my support plan with the panel. It went though with no difficulties, and in the two years since I've had small changes agreed to my support plan agreed without discussion.

Gerry

So, did the transfer to ADSA give you the chance to use different services?

Miriam

For many people it's given them a chance to make big changes to their support arrangements, and to their lives.

In my case it would probably seem to an outsider that very little has changed. I was lucky enough, even before ADSA, to have support workers coming to my home every day to provide personal assistance. On the face of it, that's still what happens. But look closer and you'd see it's very different. My support workers used to be selected by the agency that employs them. They'd arrive when it fitted into their other duties – which often meant I couldn't get up in the morning - and they saw their job as giving me personal assistance at home. Now I have the ADSA budget, I'm the paying customer. Unless there's some very good reason, I expect my support workers to be from a list of people I've approved, and to turn up at times I've agreed. My contract also makes it clear the support is needed whether I'm at home, in my office, or involved in other activities.

Joanne

If I can just pick up on that, Gerry . . . . I hope Miriam won't mind me pointing out that when she talks about what she expects from her support services, she's talking about service standards and quality assurance. In the old way of doing things, bureaucrats laboured to come up with lists of standards for services, and then professionals spent their time visiting services to see whether those standards were being met. But the people on the receiving end of services are in a much better position to decide what good service looks like, and when it's being delivered. Of course we still need to have some agreement on basic standards, but they're mostly needed as a fallback, a safeguard. When the consumers are the paying customers, they set the standards.

Miriam

That’s absolutely right.

The other thing I wanted to say about my own ADSA budget is that sometimes my health gets worse, which means my support costs go up. The Support Plan that’s been agreed includes an allowance for this possibility, but I also know that if I went through an extended period of poor health I could go back to ADSA and get an increased budget.

For me, that sort of partnership– where I’m treated as a trustworthy adult, and I can trust ADSA to stand by me – is ultimately the most fundamental and important change with this new system. I know that some people think ADSA is an open invitation to people to misspend taxpayers’ money. In my experience – and I know Joanne will back me up on this - people respond positively to a system based on trust. I know people who have been immensely proud that they’ve been able to return some of their budget because they didn’t need it.

Joanne

Yes, we’ve seen a lot of that too. It’s also clear that people are figuring out better ways of using the money. They’re ‘thinking out of the box’, with the result that they’re achieving much better lives for themselves, and those precious tax dollars are being put to better use. I’m not going to say that there’s never any misuse or wastefulness, but it’s rare. It makes no sense to let the design of the system be driven by an obsession with catching these rare cases.

Gerry

Well, you may have different perspectives, but you both seem very convinced about the benefits of ADSA. Do you have any reservations?

Joanne

I don’t have reservations, Gerry, but I do want to make it clear that this is a work in progress. It’s going to take at least another five years to complete the job. These are big changes, and not only about systems and funding streams – they’re also about old attitudes and ingrained habits. The real challenge is to keep going through a change process that will take a decade, and be willing to learn and change, and yet stay true to the principles that got us started.

Gerry

And you, Miriam? You did mention that you had some concerns.

Miriam

I suppose the concerns that I have come back to the issue of trust. On the one hand there is some unease amongst people with disability themselves about the consequence of a system that is focused so much on individuals, when there are still so many collective issues to address.. The concern is that it is separating people with disability from each other, weakening their collective political voice. A 'divide and conquer' problem, if you like. On the other hand, there is concern from families and carers, and some services, that allowing people with disability the chance to move away from services such as day centres and other settings where people have congregated and spent time together will decrease choices and force people into options that are deemed "politically correct".

I don't for a moment think there's some kind of conspiracy going on, but I do think we have to recognise that nothing is guaranteed in the long term, particularly on funding. We can all 'think out of the box', to find better and less costly support options. But people will still need paid support. An under-funded ADSA could be very bad news.   So for me it's really important that we don't relax too much – we don't know what the future may bring.

Joanne

I can say, hand on heart, that there's no conspiracy, and I've not the slightest reason to think that funding to ADSA will be cut. In fact the way that the National Disability Insurance Scheme is structured, it is guaranteed to be maintained at current levels, even if GDP drops, and to grow, as both the national economy and the population grow.   But I entirely agree that the people who depend on ADSA need to stay alert and organised. As I was just saying, our challenge is not to lose sight of the real aims of ADSA though this long process of implementation.   We need the strong voice of citizens with disability, at every level from national government down to the individual ADSA budget recipient, to help us stay true.

On the other hand, I do think it's appalling that citizens with disability have had so much of their lives defined by the need to fight a human service system that was created to assist them. I hope that ADSA brings that to an end.

Gerry

Thanks to both of you for sharing your experiences of the ADSA with our listeners today.

b) The structure of the vision

In Control Australia believes that a disability support scheme should be developed, which is directly funded by whatever iteration of the proposal for a National Disability Insurance Scheme (NDIS) is eventually adopted. Given that the mechanism for raising the revenue to fund this new scheme is national, In Control Australia believes that the mechanism for its delivery, and its governance structure, should also be national. This means that the current method by which funds for services are provided to many people with disability, through the States and Territories, needs to be overhauled, and many of the functions currently held in those jurisdictions transferred instead to the new national scheme.

The new scheme needs to be administered by a new national authority, which we have currently named the Australian Disability Support Authority. The governance structure of this new authority must have significant, majority representation by suitably qualified and skilled people with disability, together with representation by families and carers of people with disability. The new authority must be supported at the local level by highly visible and active agents, who are connected with their local community, and focused in their duty to identify and resource the support needs of people with disability. Local resources centres have been suggested by some groups as being needed in many areas, to provide support to people who access the new scheme. However these resource centres are to operate, and whatever the final list of duties and responsibilities of the Authority's local agents, these local level activities must be supported by advisory groups of local people with disability, and carers and family members of people with disability (and perhaps other local stakeholders).

The focus of the scheme must be, fundamentally, the provision of support to people with disability to live fully participating and inclusive lives in the community. It must not be oriented toward the provision of specialist, segregated "accommodation", and should avoid all pressure to create new and special accommodation "models". Instead it should be focused on enabling citizens with disability to obtain support that meets their requirements without determining where they should live. The issues of suitable housing, both in terms of accessibility and affordability, need to be lobbied for by the new authority, and acted upon by every department of every level of government. Where existing, non-complaint accommodation models are in current use, a timeframe of 2 years will be set to devolve these, with responsibility for funding and overseeing the devolution, together with the responsibility of ensuring that suitable, accessible and affordable housing is provided as an alternative, falling to the States and Territories where these models currently exist.

The delivery of the new scheme must be wholly through the provision of individualised funds, which provide to the individual with disability the control over what supports they receive, how those supports are delivered, and what those supports achieve by way of outcomes. The responsibility for allocating these funds and monitoring the outcomes for individuals will fall to the new authority. Responsibility for ensuring that adequate support and service infrastructure of a suitable quality is available to meet demand, will fall to the State and Territory governments.

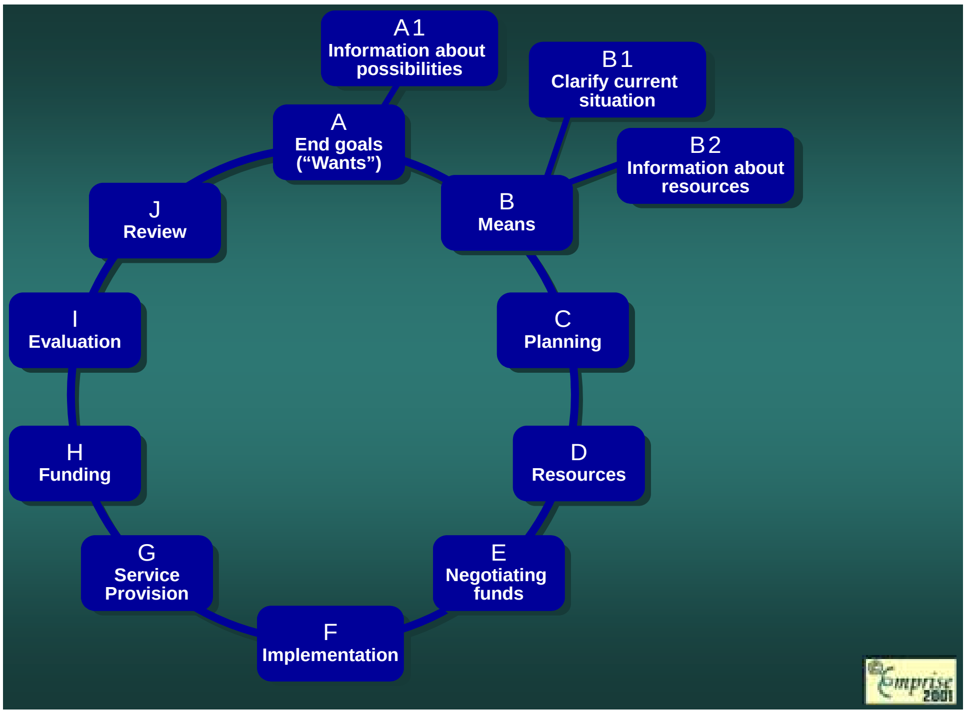
c) The mechanics of the scheme

The details of how a new scheme is to be constituted, governed and implemented are provided in the Part Two, Section 2.3 and Section 4.

This section will focus on the support and service structures that exist around a person with disability. The purpose of this is to identify who is in control of the various aspects of support arrangements, and highlights how individualised funding and self-directed support arrangements enables people with disability to be involved in decision-making at many more points in the support/service delivery cycle than do traditional, block-funded arrangements.

The EMPRISE circle

The EMPRISE circle, with reference to the diagram below (the acronym is simply formed from combining the key processes in the circle below at A,B,C, D, F, G, and I), provides a tool for analysis of support arrangements that are in place for people with disability. All of the processes below take place within a support arrangement, and it depends upon the arrangement itself as to who controls which process, and the extent to which a number of different people or agencies are involved in each process. A total institution would, for example, have control over all aspects of the arrangement, and the distinction between the various components would sometimes be hard to decipher.



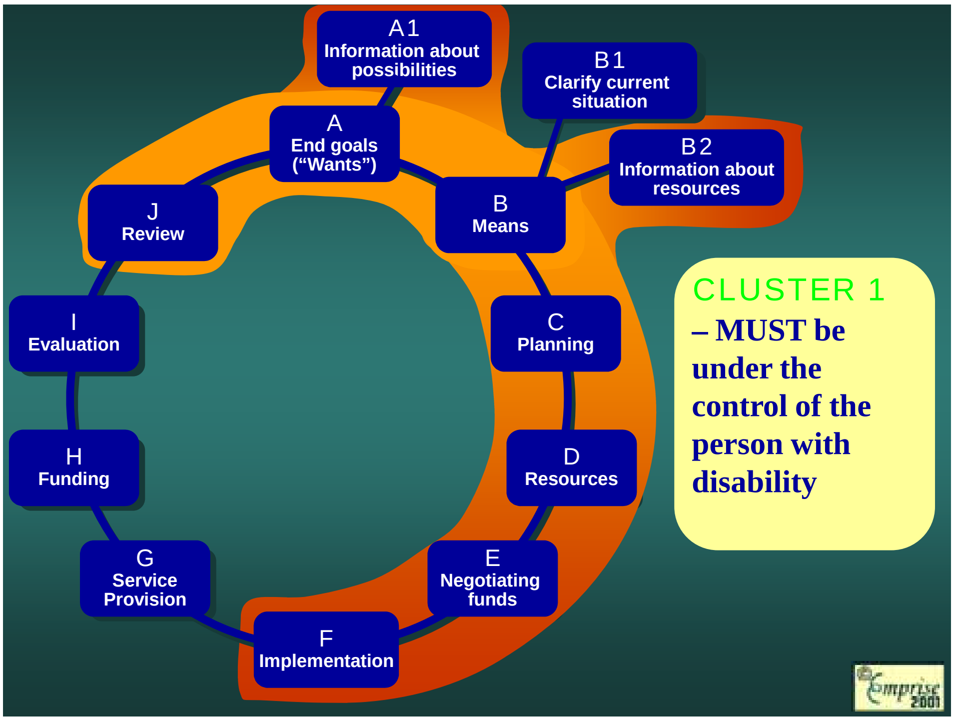
The sections **A and B** (including A1 and B1 and B2) are processes that in many instances need to be intentionally promoted with a person with disability, to provide the overall vision for what ultimately the support arrangement is going to achieve. What individuals in the community refer to aspiration or ambition tends to drive our strategies and define our needs, and this phase needs to be driven by the person who will be the support recipient, perhaps with assistance, but needs to remain separate from the formal aspects of support and service planning, because in effect it determines what systems responses are required.

Sections C – F relate to the processes of planning to meet the identified aspirations, and putting in place the resources that are required to achieve these. Some of these resources will be available generally and to the individual, based on their circumstances, but some will be specialist and will need to be encouraged and funded by the new Authority.

Section G refers to the delivery of the support, either through a specialist service provider or a contracted generalist service, or by means of direct employment of staff.

Sections H and I are typically system-led, in that the delivery of funds, and the evaluation of the use and impact of those funds, are important to acquit and justify.

The final **Section, J**, however, relates specifically to the outcome achieved for the individual, and denotes an accountability for that individual, which feeds into the next planning cycle.



A1
Information about possibilities

B1
Clarify current situation

A
End goals (“Wants”)

B2
Information about resources

J
Review

B
Means

I
Evaluation

C
Planning

H
Funding

D
Resources

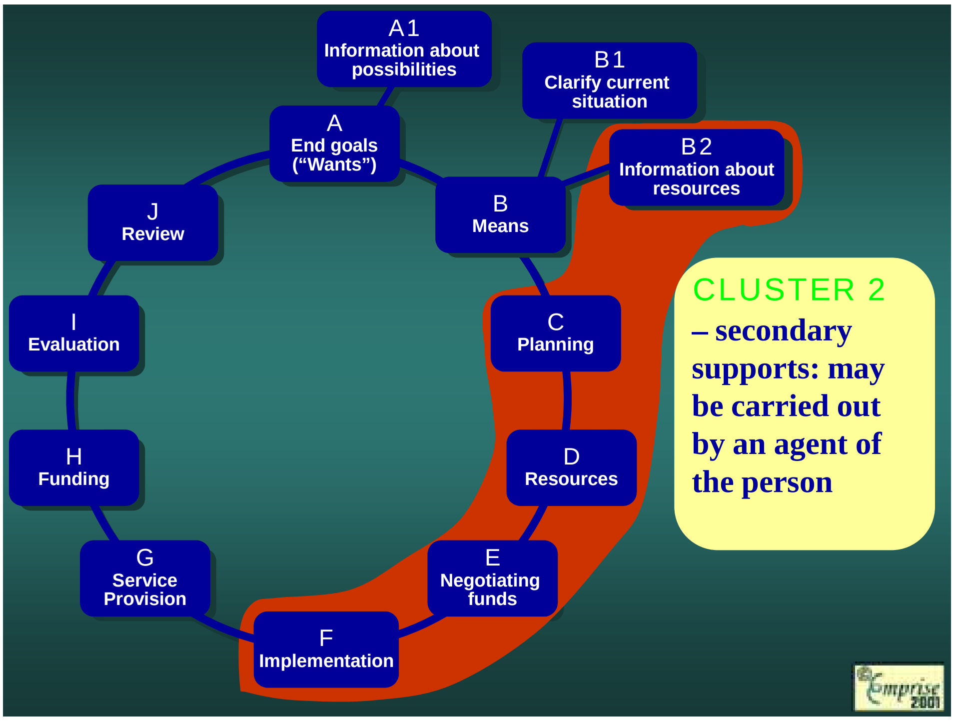
G
Service Provision

E
Negotiating funds

F
Implementation

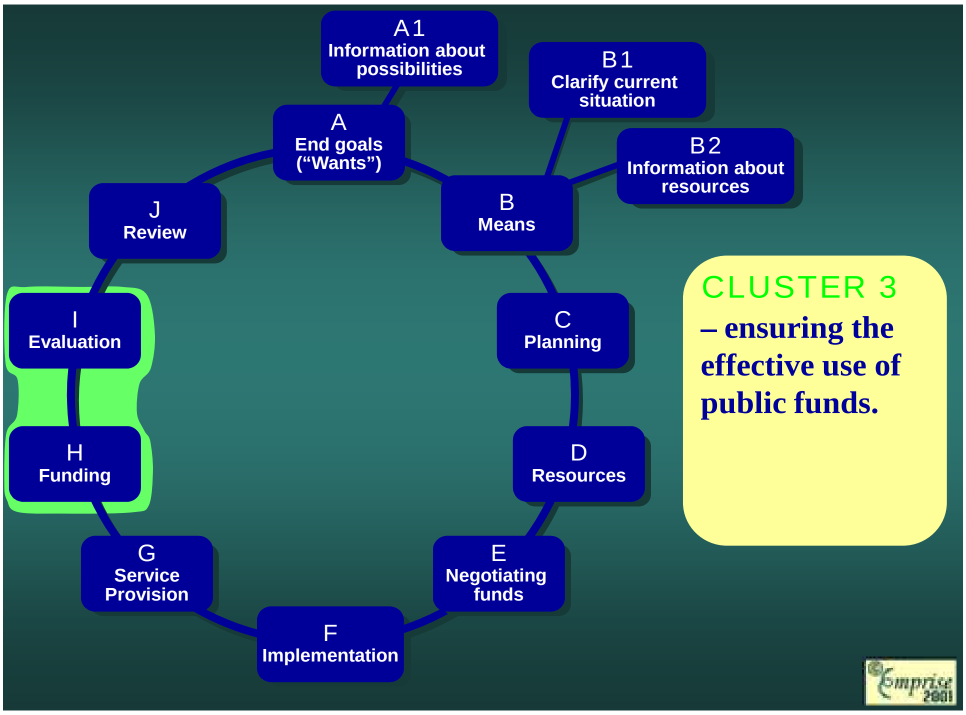
CLUSTER 1
– MUST be under the control of the person with disability

As the slide above indicates, in an ideal self-directed model, all of the sections, with the exception of G, H and I, must be under the control of the person with disability. Importantly, this means that the supports which are delivered by means of a service agency, or a set of individuals working directly for the person with disability, are answerable to a set of strategies which are working toward achievements which are agreed by and meaningful to the person with disability.



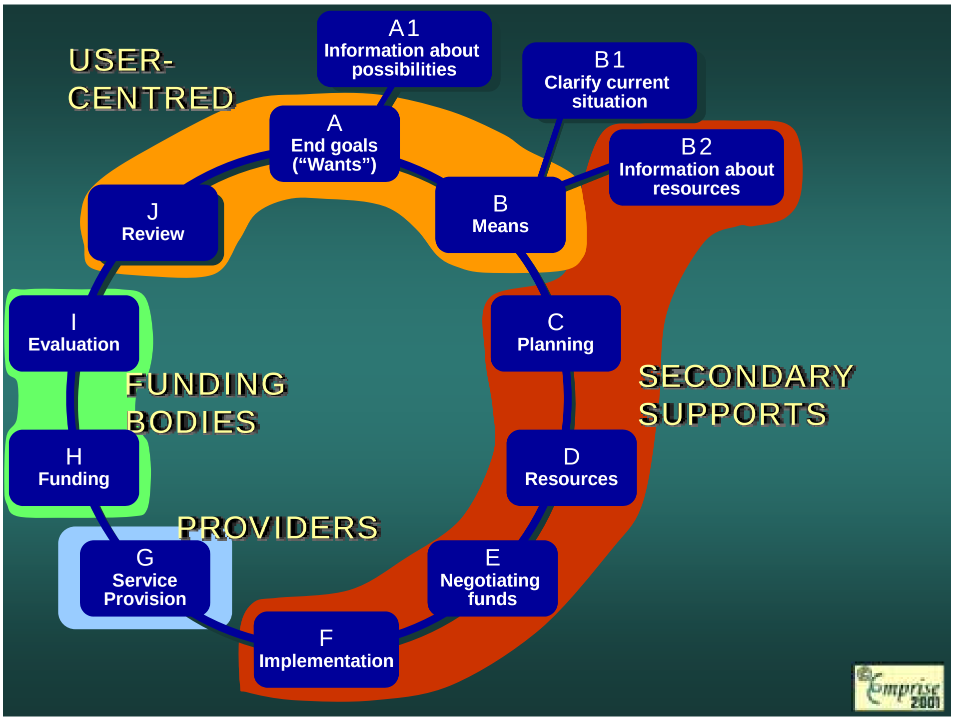
CLUSTER 2 – secondary supports: may be carried out by an agent of the person

Sceptics of individualised funding and self-directed supports often choose to interpret its mechanisms as meaning, literally, that money is just provided, without reference to any planned context, to a person who then spends it in any way they can to get basic services. While the shift from funding services to funding individuals is straightforward and significant, in fact all advocates of individualised funding and self-directed supports stress the need to make available to people with disability secondary supports, which can assist them in any stage of the processes in which they are in control. The diagram above demonstrates why it is important for these secondary supports to be separate from both service providers and officers of the system (usually government department officials or case managers), as these staff have other duties to perform which mean they cannot advise or advocate solely for the person with disability. Some of the roles played by secondary support providers are assistance with Person-Centred Planning, the “brokerage” function, and the role of fiscal intermediaries.



CLUSTER 3
– ensuring the effective use of public funds.

Proponents of individualised funding and self-directed supports have never advocated for the provision of public dollars without due accountability. Clearly there is a significant role for the state to play in providing these funds, and ensuring accountability for their effective use back to the public. Individualised funding arrangements always come with a mechanism (the simpler the better) for detailing how much funding is available for the individual, how those funds are spent, and what need they have met or goal has been achieved. **Section H and I** are then clearly under the control of the department or Authority which is responsible for both the provision of public funds, and the effective use of those funds.



The above diagram summarises the various levels of responsibility and control. It is worth noting that in **Sections C – F**, there will be a dialogue, a negotiation between the person with disability (and their associates, and potentially somebody in the role of secondary support) and the funding body. It is characterised as being under the control of the person with disability here to emphasise the importance of the linkage of those negotiations to goals and aspirations, and the needs associated with those, which have been identified previously in processes that remain totally under the control of the person with disability.

We have at the start of our submission highlighted a key principle of role clarity (see Principle 1.10). The above diagrams help to articulate what these roles are, and begin to explain why clarity is important. In Control Australia believes that blurring the roles, or having staff or other people associated with certain sections take on roles within other sections, distorts the optimal operation of any support delivery model. For example, there has been a tendency to utilise case managers, who also have purchasing and contracting powers, to assist in the planning processes for individuals. This process clearly has to be under the control of the individual, supported by independent people. We have stated that this **process (C)** involves dialogue with the state body, which may be represented by a case manager, but this is not the same as utilising the case manager in the role of supporting the individual to formulate a coherent plan.

Finally, In Control Australia believes that this analytical tool is a useful way to monitor and report on Australia's compliance with the CRPD, in relation to the way that supports and services are funded and monitored, and will greatly assist our reporting of the extent to which people with disability are in control of their own supports, and, much more importantly, of their own daily lives.

d) Funding Secondary Supports

As explained above, the EMPRISE circle shows how the current system fails to meet these requirements. It also indicates how roles and responsibilities must be allocated between the major players in a new and better system.

This allocation of roles and responsibilities leads logically to a structure that has a ‘third arm’, separate both from government and from the delivery of services. This arm provides a secure location for those elements that exist solely to support the choices and rights of persons with disability. In the new system, these include assistance with developing and implementing plans to use individualised funding, but the third arm also offers a ‘home’ for existing activities such as advocacy. As many of these activities will require funding that originates from government, the independence of the third arm needs to be preserved through special arrangements for governance and accountability.

Although, as argued above, there must be a separation between the responsibility to ration public funds and the process of developing plans to suit the individual, ultimately the two sides have be reconciled. A decision must be made to provide the individual with funding, at a level that balances individual requirements against overall budgetary demands. In a case-managed system this is typically a judgment made by the case manager, with no involvement or representation of the person requiring funds, and with no transparency. This type of arrangement utterly fails to satisfy the principles that we have set forward for a new system. Better alternatives include form-based assessment that yields a calculated allocation of funding, or a process of face-to-face negotiation when individuals are able to argue their need for funding with decision-making staff from the agency that rations the funds.

In Control is recommending an Individualised Funding system that employs both of these methods to arrive at a final allocation of funds to the individual. There is further discussion in Part Two: Section 2.3 about the operation of this system, but in essence the process would work as follows:

a) An individual requesting funding in connection with their disability would first be assessed to check that they fall within the range of people that the Authority exists to assist. (Our proposals for eligibility are set out in Part Two: Section 1)

b) A questionnaire is completed, with their involvement, to identify in everyday functional terms the amount of additional support they need, and this is used to calculate a guideline figure for the level of assistance that they can expect to receive from the Authority.

c) The individual, with assistance from sources of their choice, prepares a written plan that sets out the way that they propose to use the funding, and the estimated cost. As they do this, they are aware of the information that must be included in the plan, and the rules about the uses of funding that are acceptable.

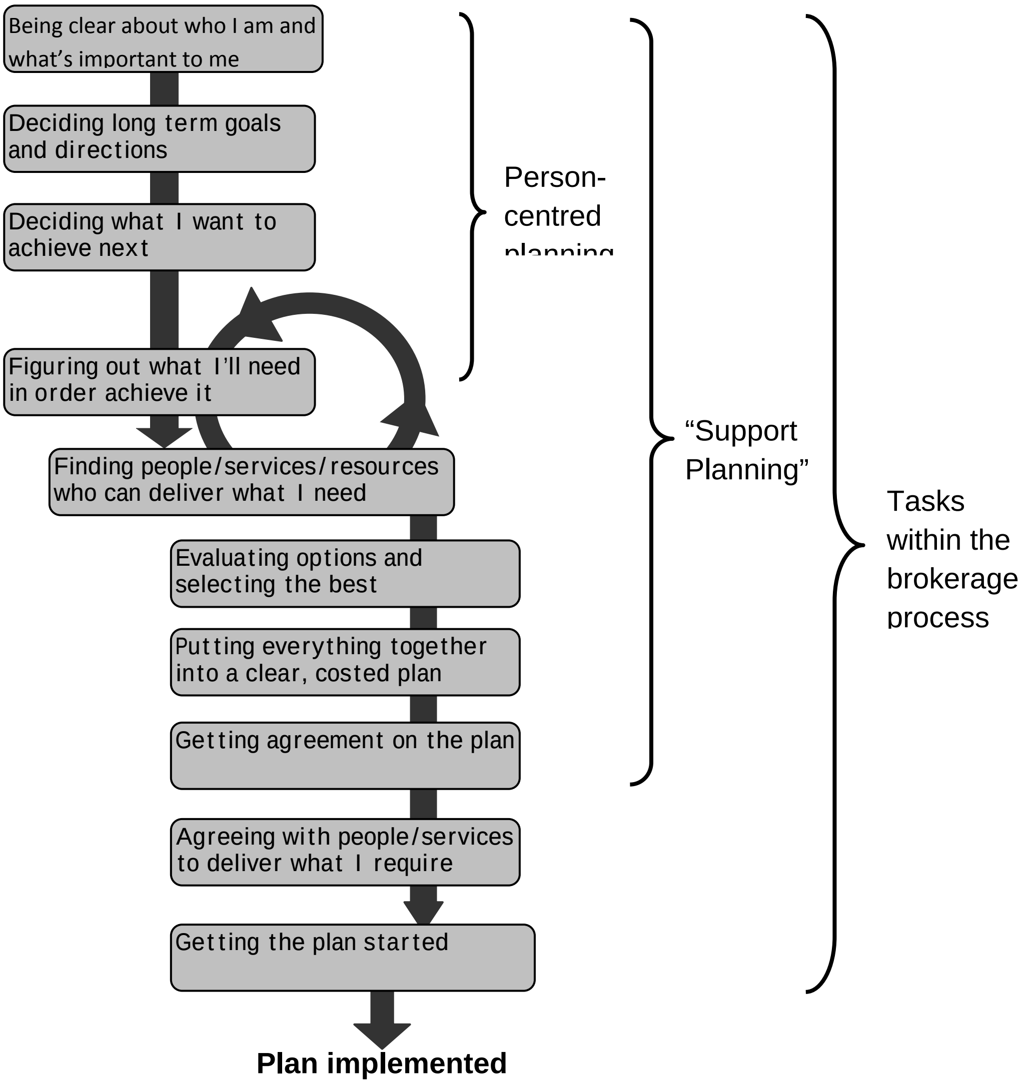
d) The plan is submitted to the funding authority. It may be approved without discussion, but otherwise there will be a meeting between the person and/or their representative and representatives of the authority. The process of negotiation may cover not only questions of cost but also such matters as any risks presented by the plan.

e) Funding is released to the individual, or to an agent acting on behalf of the individual, and the plan is then implemented. The individual will usually have freedom to change use of funds within the overall plan – for example to move the delivery of agreed type of support from one provider to another – but where the authority had justifiable concerns it would be able to stipulate extra conditions.

f) The Authority carries out periodical reviews to confirm that the plan has been implemented and is achieving the aims that the individual had intended.

e) Brokerage: planning and organizing supports to meet individual requirements

In Section 2.3.4 we reviewed international interpretations of the role of broker. In this section we develop a conception of the role as it would fit the individualised funding system that we are proposing.The process, as summarized above, requires that a set of tasks is completed that will translate a guideline individual budget into a successfully implemented set of supports and opportunities. Some people will have the skills and resources to do these tasks for themselves. When the sum of money is small, and perhaps being spent on a simple package of assistance from one agency or individual, the job may be easy enough. In other situations, however, the plans may be intended to achieve a radical change in lifestyle (for instance, from institutional living, or living in a staffed group home, to living alone); require a large amount of money, call for a complex mix of paid and unpaid supports, and present risks and uncertainties that need to be evaluated with care. Moreover, the tasks require a range of very different skills, and wide-ranging knowledge: Thinking up creative solutions; writing documents; liaising with health professionals; negotiating with providers, converting unit costs into annual budgets; and many more.



If these tasks are not completed well, the outcome will not make the best possible use of funds to improve or sustain the quality of the person's life. This is not in the interests of the individual or the taxpayer. Furthermore the potential of individualised fund to empower people with disabilities, and to improve the range and quality of support services through the choices they make, will not be realized. For these reasons it is extremely important that people using individualised funding have access to support to complete these planning tasks.

This support may come from a variety of sources, including the person's family and friends, from other people with disability, and from professionals in the person's life, such as social workers or support staff. Help from these sources should be welcomed and encouraged – not only for reasons of cost, but because they have special advantages. For example, family members may be unique in their ability to understand someone who cannot communicate through words, and the peers of a person with disability can be especially effective in helping someone to envision a different and better life for themselves.

In Control Australia believes, however, that there is nevertheless an essential role for a source of help with planning that –

- is independent of government and services;
- offers assurance of standards of competence and ethical practice, underpinned by a system of training and accreditation;
- provides a service to the individual (and/or their family) on the terms the individual stipulates.

The need for this type of help was identified by the parents of people with disabilities in Canada who first defined the individualised funding model, and who named it as the service broker role. (Internationally it is now more commonly known as the support broker role, to emphasize that it is not only concerned with formal services.) People with disabilities and family members have reiterated the need for the provision of broker services in other countries, including England. (See Dowson 2008).

The new system, in its design and funding, should make provision for independent broker services, and for financial support to organisations such as disability peer groups which are able to offer components of brokerage. On the other hand, the right way to ensure that broker services are available, and the appropriate level of investment, may be best decided at a more local level, and we recommend that this should be one of the responsibilities within the new third arm of the system. In terms of broad principle, independent broker resources can be created in two ways:

A. Supply side commissioning:
   One or more organisations, independent from government and unconnected with the delivery of other services, are funded to offer broker services. The brokers are recruited as salaried workers for the agency. Standards of service are ensured through line-management within the agency.

B. Demand-led development:

> Action is taken to encourage people to train to work as self-employed brokers – for example by running local cost training courses. People who demonstrate their competence, independence, and ethical working practices are accredited and monitored by a local regulatory body. The brokers are paid on a fee-for-service basis.

Supply side commissioning has the attraction of being a more familiar and predictable development route. However, it results in an inflexible resource that may prove wastefully large or too small to meet demand. The choice of brokers is likely to be limited, and the salaried status of the brokers will weaken accountability to the person being assisted.

In contrast, the demand-led approach generates a market in which good brokers will flourish. Brokers from a wide variety of background will offer a high level of choice, and there will be a strong sense of accountability to their customers. Provided that there is sufficient funding for the payment of brokers, the size and overall cost of broker resources will change to match demand.

The main difficulty with the demand-led approach is that it requires an arrangement through which people requiring broker services can use public dollars to pay the broker of their choice. Including the cost of broker services in the main allocation of funds is not a satisfactory answer: it encourages people to reserve all their funds for support services, even when they need broker assistance, and in any case the broker services are needed before the main funding has been agreed and released. The most promising alternative is a system by which people requiring broker services are authorized to obtain a set number of hours (linked to the guideline allocation figure) of broker assistance. Individuals can then choose to 'spend' these hours on any accredited broker. The broker is given evidence of the contractual agreement which they can then use to claim for the hours worked.

Further work needs to be done to agree the detail of policy on the provision of broker services. However, at this stage In Control Australia recommends –

- Commitment in policy to the provision of broker services that represent a skilled, trustworthy, and independent service to assist people in the development and implementation of support plans
- The development of pilots, with comparative evaluation, to create broker services using 'supply-side' and 'demand-led' methods.
- That where fee-for-service brokers are established, they should operate within local regulatory systems that are overseen by people with disabilities and family members.

In Control Australia would also like to emphasise two further points regarding broker service development:

1. We recognise that, in some States and Territories, existing human service staff will need to be redeployed, and that the creation of broker services will offer new work opportunities. However, we strongly believe that staff who wish to take this career route should be re-trained, assessed on their standards of practice, and not simply assumed to have appropriate skills, knowledge, and values. Furthermore, the creation of brokerage services should not be biased towards commissioned

brokerage agencies (i.e. supply side initiatives) on the basis that this provides an easier redeployment route.

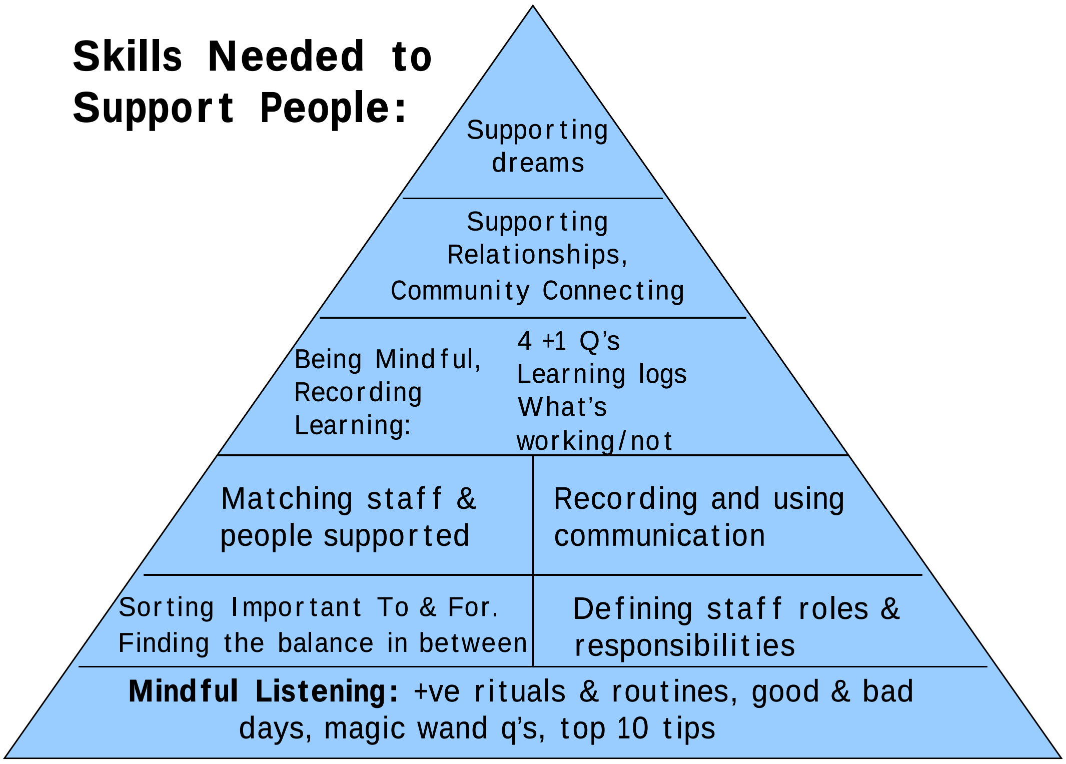
2. It is extremely important that support brokers are understood to offer a service only to the people with disabilities and families who are their customers. No lines of accountability should exist between brokers and the new Authority or state human services. The procedures for assessing eligibility, or the level of funding, or the acceptability of the support plan, should not depend on the involvement of a broker. In particular, brokers must not be required to make judgements or decisions on the acceptability of risks in a support plan (though they can of course encourage the people they are assisting to consider risks with due care). If brokers are expected to perform duties on behalf of government or state human services, their independence will be undermined, and the fundamental structure of the system will be compromised.

f) Delivering supports to facilitate inclusion – Person Centred Planning

Planning around individuals outside formal services is very important – particularly where they have long been in excluded situations, and/or where they and services have low or negative expectations. Trained facilitators will be needed to encourage this to happen, and such facilitators are best located within the new third arm.

On the other hand, much person-centred planning will be incorporated within support planning. This will help to ensure that the planning process leads to the required actions and outcomes. People offering assistance with brokerage – not only paid brokers, but also family members, peers, and others, will require training in the essential tools of person-centred planning and thinking.

However, an individualised funding system motivates providers to deliver what individuals want. It causes a shift from person-centred to customer-focused. Providers will need to become competent in responding to their customers in every aspect of their work. So while specific person-centred planning procedures and methods have their place, the main concern should be on person-centred thinking and person-centred approaches.



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g) Safeguards

In Part Two, Sections 2.4.2 and 2.4.3, below, we discuss some of the real and perceived risks associated with the introduction of a new system based on individualized funding, from the point of view of all stakeholders, including human service staff, service providers. However, we are aware that there are some basic concerns about risks associated with the individualised funding model, and want to address those here.

These concerns spring from the intention of individualised funding to increase the freedom of each funding recipient to have more choice how they live their life and, as part of that, have more control over the money spent on their supports. This freedom is perceived to increase two kinds of risk: firstly, that the person will place themselves in a dangerous situation, and come to harm; and secondly that they will misspend the money, thus wasting public money that could be put to better use.

In response it needs to be said immediately that no system will eliminate either of these risks entirely. As the history of institutional care shows all too clearly, even a system that deprives people entirely of freedom cannot guarantee that they will be safe. Discussions about these risks need to focus on whether, when compared with the system that is being replaced, they will be reduced or increased. It is also important to measure the size of risks against the right of people with disability to take risks, just like other citizens, in pursuit of the life they prefer.

Moreover, the risks and benefits of individualised funding depend on the way in which the IF system is designed. In this submission, In Control Australia is proposing a system that pays due attention not only to the rights of citizens with disability but also to the need to ensure that public funds are used well, and that vulnerable people are protected against harm. Individualised funding, as we hope it will be implemented, has the following strengths:

- Individualised funding places control over the process of planning with the people who have the greatest interest in developing plans that will deliver the best outcomes and make best use of funds. People planning their own future have more time and motivation than, for example, a case manager with responsibility for many clients.

- Individualised funding allows the person with disability (supported when needed by family and friends) to decide whether they are getting quality from their support providers. As with commercial markets for other citizens, providers will have business and career incentives to deliver to the requirements of each customer. Market pressures serve to drive up quality and efficiency. Bureaucratic service inspections have the more limited function of ensuring minimum standards and safeguard.

- A system based on role clarity, with a transparent process of negotiation to decide the amount of funding that the individual will receive, provides the foundation for a relationship of trust between government and individual. This is not to suggest that breaches of trust will never occur. However, and paradoxically, a system that is not perceived to be trustworthy encourages people to adopt behaviours that are wasteful. For example, if people fear that the government will not increase the assistance they need to match a future increase in their support needs, they have good reason to ‘talk up’ their current needs and stockpile any money that exceeds their requirements. In a system based on trusting partnership, more people will work to take only what they need.

- The negotiation to agree the amount of funding establishes a contractual relationship between the individual and the agency distributing funds. The individual receives the money on the basis that they are accountable for its use, with the range of acceptable uses set out in the Support Plan. This sense of accountability is completely absent in systems where services are arranged by a professional, and the individual is merely a passive recipient.

- This negotiation also provides an opportunity for the representatives of the funding agency to stipulate additional safeguards – perhaps to require that the funding is held and managed by an intermediary agency, or to require that someone has clear responsibility to monitor the delivery of supports. This does not mean that the funding agency will always be pressing for a reduction in the cost of the support plan. For example, the agency might consider that the individual has under-estimated their need for support, and so offer to increase the allocation to cover more hours.

- In all these tasks and discussions, the person with disability will have access to a range of supports. A good individualized funding system will welcome and facilitate the involvement of family members and other allies of the person, while not placing unreasonable burdens on them. Paid brokers will be available, alongside other sources of brokerage, to help people decide how to use the funds, arrange for the delivery of supports, and seek out appropriate community opportunities. They will also be a variety of ‘secondary support’ services that can take on the practical burden of making sure the supports operate reliably –including fiscal intermediary agents to manage the money and support coordination.

In combination, these provisions mean that the system rightly operates from the default assumption that citizens with disability are trustworthy, and best placed to decide how they should live their lives and obtain their supports. However, the system still enables the government to fulfil its responsibilities to ration public funds and protect vulnerable people, through the use of mechanism that can be brought into play when, and as far as, is necessary.

In addition to the safeguards that can be built into the operation of the new system itself, primarily in the relationship between the person with disability, or their representative, and the funding body (and also between the purchased support workers and/or services), In Control Australia believes that the availability of adequate secondary supports, and the funding required for these, can also safeguard the quality and integrity of the support that the person with disability ultimately receives. This will include assistance with envisioning a future, undertaking person-centred planning, with managing finances that come to the person as a result of their agreed plan, and with the employment, training and supervision of paid staff.

In addition to preventative safeguards, In Control Australia joins with the rest of the disability sector in proposing that a well-funded, robust and truly independent advocacy sector is the primary referral point for people with disability for whom the new system is not meeting their needs. We have proposed how a scheme can fund a wholly independent body which oversees the development and implementation of independent advocacy, that is available throughout Australia (see diagrams in Part Two, 2.1.3 and 2.3). Independent advocacy, which has slowly but steadily been developed in Australia, is key to ensuring that people with disability who need support under the new scheme, get access to that support, and that the quality of that support is consistent with the identified needs of the individual. Systemic advocacy can continue to monitor the successes and shortfalls of the new scheme, and provide reports and information to the new Authority, which in turn can lead to ongoing system changes for improvements in support and full coverage in areas of neglect.

The new system must also have a strong, complaints handling and monitoring body, with powers to intervene in service and support contracts, and to compel the cooperation of service providers, in order to arrive at swift and effective resolutions. If the governing body of the new authority is, as we recommend, primarily constituted of people with disability, with representation from the families and carers of people with disability, then this complaints handling and monitoring branch can be attached to the authority itself, and many of the powers it requires can be included in the authority's charter. However, should the authority come under the direction of a government department, then it is vitally important that the complaints and monitoring body be separately and independently constituted, and that it also have powers vested init similar to those which are currently able to be deployed by State and territory complaints and investigation bodies.

h) Case Studies

We conclude this opening section with some real-life case studies, which demonstrate different versions of individualised funding and/or self-directed supports, and the impact these have had on the lives of people with disability, and upon the lives of their carers and families.

1. Being In Control through Direct Payments – Robert's story

Background

I am a 44 years old professional, am married with an 8 year old son. Whilst travelling overseas in 2005, I was the victim of a 'hit and run' motor accident that almost took my life. I now have permanent tetraplegia C-8 spinal cord injury.

Following this traumatic injury, 12 months was spent in medical institutions overseas and in Australia. I relied on assistance from others to complete the necessary activities of everyday living and medical care.

Upon release from acute rehab a life of independent possibilities was anticipated. I looked forward to enjoying the relative independence of community living that other citizens have the benefit of.

I was initially allocated 14 hours per week of personal care provided by government-operated home care provided. My hours were later extended to 32 attendant care hours.

Services Provided

Twice per day, personal assistants were to attend me at my home, helping me to get ready for work in the morning and assisting with showering and toileting at night. Although the hours of care were acceptable, there were countless problems with the service delivery that made the experience stressful and traumatic for me and for my family.

Firstly, the workers providing my personal care were accountable only to their employer, the government-operated home care provider. They were totally inflexible in their approach and unable to mould the service to suit my individual and family needs. On many occasions, I was obliged on a Saturday and Sunday morning to get up at 7 a.m. as it was the only time that they could find a carer available for me.

The situation during the evenings and weekends was also very unsettling for my family. The home care provider could not always tell us in advance which carer was on duty or what time they would arrive. My wife, who was struggling to cope with the *lack of routine as well as work full time and care for our son, was often upset by having to wait for carers to arrive. On one occasion my wife left early to attend to family affairs. I was left in bed trusting that the carers would arrive and assist me as they were timetabled to, I was forced to spend the whole day in bed when they neither arrived nor answered my calls. As the incident occurred on the weekend, there was no answer at the home care provider and no after hour's number to call for assistance. This incident was very detrimental to the quality of the entire family. Since that time, my wife could never leave home until I was safely helped to my wheelchair, for fear of repeating the incident.*

Not knowing who was coming into our home was also a major concern for our family. Many carers interacted with our son and although were no malice intended, sometime the amount of attention he received from them was unsettling and at times inappropriate and disruptive to our family culture.

Directing My Support

When an opportunity arose to participate in an Individual Funding Pilot Project, I took it without hesitation. Through this project, I received the funding to organise my own supports. I chose to use a financial intermediary to cover the workers compensation insurance of workers I employed and to pay their wages etc and to offer me other assistance if I needed it.

While society has often disregarded the potential of people living with disability, I saw my involvement in the pilot project as an opportunity to prove that I could once again be in charge of my own life and inspire other people with disability to do the same. I never considered myself as a passive recipient of care and now enjoy the responsibility that comes with participating in this initiative. I personally believe that the society need to build the capacity of people with disability, their families and their contribution should be both encouraged and supported.

The Convention of the Rights of People with Disability recognises the "importance of people with disabilities in their individual autonomy and independence including the right to make their choices". The preamble also states that they must be given the "opportunity to be involved in the decision-making process about the policies and programs including those involving them" (UN, 2006). With my participation in the pilot project, I am able to hold, administer and manage the budget allocated to my care. Since December 2006, I've been able to recruit and train my own staff. I am also able to organise the timetable that suits my individual needs and those needs of my family.

Outcomes

*Some of the workers that I recruited were employed by the government-operated home care provider. I had to basically retain them so that the service they provided suited my specific needs. As the employer and recipient of services, the quality of these exponentially improved. Nearly 3 years after being recruited in the pilot project, I have had the same personal care assistants providing my care. I believe that I have treated them fairly, given them a fair salary and provided with some levels of flexibility. In return, they are able to attend to my immediate needs even on a short notice. Instead of being considered just as carers, they are almost part of our family**.** Over the years, we've developed a high level of mutual respect and trust to a degree that they are entrusted with the keys to our home.*

We don't have to worry anymore about whether or not the carer will be coming. Having carers coming to deliver care at home can be an invasion of privacy but at least my family and I know exactly who is coming. My son knows our 3 carers well and is very familiar with their timetable too. He no longer hides under the table in fear when the doorbell rings.

"Overall, my personal involvement with individual funding, that I control, has improved my family and my own quality of life and generally enhanced our community participation".

2. The Story of Debbie and her family

Background

I am a 27 year old year Aboriginal woman who grew up in an abusive household and was removed and placed in care. In spite of the setbacks which have happened to me, I have always wanted to be a good mum. Family is the most important thing in my life. My partner and I have had 4 children together (all under seven) and they all have ADHC, Oppositional Defiance Disorder, learning disabilities, behavioural issues, epilepsy and all are currently waiting diagnosis of Autism Spectrum Disorder. To complicate matters further, my partner and I both have disability or medical conditions. Between the doctors, the therapists, the services, the paediatrician's and the school commitments life at our house resembles a bit of a circus. Sometimes my children's needs are so great that it all gets on top of me. It has been a very frustrating and heart breaking journey to date. Services come and go, but no-one ever stays long enough to make a lasting difference. Please don't get me wrong, I appreciate all of the help I have gotten but I think that services take a look at our situation and run in the other direction. We're in the too hard basket. A service will come to the house and do an assessment, but then I never get copies of the reports or support with what to do next. I feel like I am trying to find my way in the dark and no one ever really listens to what I want to happen next.

Tailoring our own supports

We were referred to the Early Start: My Plan, My Choice program through our worker at Marumali (a community health service for Aboriginal and Torres Straight Islanders) and couldn't believe it when my 3 year old son, Denis was accepted onto the program.

We met with a facilitator and she explained that this funding could be used for whatever my family needed, and that I would have the final say in all of the decisions. We created a Child Centred Plan together to look at what were the most important areas to Denis and our family. It took a few sessions to get my head around it and stop asking permission to do what Denis needed/wanted. Instead of being a typical case manager telling me what to do the facilitator is like a guide. I could talk to them about what was going on with Denis and ask for advice. They never kept information to themselves and would send through details of services that might be able to help in the future.

We were able to use the funding to fix up the fence so that the kids wouldn't run out onto the road or be in danger in the front yard. We were able to fix up our car so that I could drive them all to school and their appointments. And I was able to buy lots of educational toys for them to play outside and burn off some energy. This was the first time where I felt I was being listened to and supported in making the right choices for us.

My Hope for the Future

All of my children are under 7 years old, so we are at the beginning of this journey with a long, hard road in front of us. I think that this experience has been really good for us as a family. Having our kids able to be safe while they play outside has been a huge relief and has improved our relationships. I am submitting another nomination form for the Early Start program and am hoping that we may get lucky again because there is still so much to be done. I worry about what to do and where to go next and am scared that it may go back to the way things were before I had the final say. I have heard lots of stories from the facilitator about the great things others are doing when directing their own supports and doing amazing things with their lives. But it is such a long 'in between' before my kids would be eligible for anything like that. I want my kids to be strong and independent and my biggest hope is that my children grow to be happy and healthy.

3. Being In Control with secondary support – Clare's Story

Background

After being allocated a self managed community participation package to provide 24 hours of support per week, in one year our family has moved from a very poor needy situation to a life of joy, activity and learning. Clare, my daughter, who has a dual disability has now valued physical and social roles as she is an artist in her own right, a cook, a volunteer, office worker, weight watcher, trainer, commuter, a citizen, shopper and valued community *member. All of this has been achieved through a very carefully planned self managed program.*

Self-Directed Funding

As part of a self management model in NSW our individual funding was allocated to a service provider. The service provider 'holds' the money on our behalf, pays for supports and services that we determine and organise. They provide case management and planning assistance as and if we need it. They also are the legal employers of staff and hold workers compensation insurance to affect this.

After discovering that we could manage Clare's life ourselves, the wheels moved very fast. A dedicated consultant met with us several times and we decided to set up a 'circle of support'.

Supported decision-making – circles of support

The circle was selected by Clare and was made up of her peers, twin sister and close family friends. The people involved had an understanding of Clare's life to date and a wish to make things a whole lot better.

The group met and with the help of a facilitator we began to plan a new beginning for Clare. From a room full of charts highlighting Clare's interests, needs and goals we extracted key areas to develop.

In a very short period of time Clare was working with an artist once a week producing amazing, vibrant, colourful canvases. Clare has gone on to produce Christmas cards, occasion cards, business cards, invitations using her artwork, and has held several successful art exhibitions. The above activities have allowed her to add philanthropy to her list of valued social roles, as money raised went to St Lucy's school – a school for young disadvantaged children. Art has also brought her fame and recognition as she has won the North Sydney Disability Art Prize two years running. After three years, Clare is still happily painting one day a week and developing as a very fine artist.

Living an Inclusive Life

The circle of friends along with Clare designed a flyer placing herself in her community as a volunteer. This has led to a number of supported job opportunities and experience has been gained in real estate and architectural offices. The skills learnt from these supported voluntary positions are numerous and the different environments have improved her social skills developed new relationships and offered many opportunities to travel train.

The positive changes in Clare over this very short period of time have also encouraged her to think about herself, her image and appearance. Her medical condition calls for a lot of medication which in turn causes massive weight gain. The support circle encouraged Clare *to join Weight Watchers and work with a Personal Trainer, again all possible through the flexibility we have through managing her supports and the results have been very positive.*

Growth and Development and becoming independence

Clare's growing confidence in herself and her community introduced the opportunity for her to consider independent living. Over a two year period the mood was right to look at and discuss an independent existence. In May 2009 Clare moved into her own unit with the aim of taking on a companion in the future.

Support for Clare then took on a different focus as we now needed to concentrate on living skills, budgeting and safety. The flexibility of managing our own supports allowed us to employ people that would assist and support Clare through this very big transition and plan on a daily or weekly basis her future needs.

CapacityBuilding

We have been supported through a bi-monthly family seminar program that has supported us and others to develop their capacity, skills and confidence to realise our visions for the future.

It was really important for us to support Clare to have opportunities that others have, such as moving out of home. She was ready and we needed to support her capacity, and it was about setting her up for the future. It is reassuring for us to know that Clare's supports are able to change as she continues through life and that this is not fixed by a program.

It is humbling to reflect on the incredible journey Clare has had to date. She has moved from being a timid, frightened and inactive person to a lady of her community, happy and adventurous.

4. Being in Control - lifestyle outcomes and planning for supported living - Sam's Story

Background

My son is now 23 years old, he loves the outdoors, listening and playing music, he likes a beer. My son is autistic with limited verbal communication and is enjoying a fantastic lifestyle thanks to our ability to manage his supports. When he was about to leave school and we were looking at post school options, it was lucky that I read the fine print about self managed options. I am just eternally grateful that I read the fine print on the paperwork we did when he left school. And if I hadn't read about SM, I wouldn't have known about it otherwise, no one seemed to know about it. At the time we were just about to move from the city to the country and self management sounded very exciting and also a little scary.

Developing our Capacity

We have been supported through secondary supports to grow in confidence and our skills and capacity to manage our own supports. We are off and running, we are confident in what we are doing and know that we have the support if and when we need it to work out any issues. There is security in knowing I have that support. I have witnessed the capacity of others also growing through the seminar program. . We get the support, information, networking and capacity building. I can see the change in terms of the level of confidence that I now have and others who manage their own supports.

Direct Payments as an option

We now have the confidence after three years that I can imagine running our supports in conjunction with someone who has the insurances and the payroll side. For me that is something I do not want to embrace.

Some families may want more control in the financial area. I envisage it being streamlined with something like In Control do with their debit card. And maybe that is when families have been on board for a year and they are comfortable and they are happy and have been to some of the training seminars and when they feel more comfortable they can choose more control. For myself I don't have the time to process the payroll and it is not something that I have thought about for myself. Other families may want to do this. Different levels of support for families. This is the beautiful part of it, it is open for so many different ideas to come in based on peoples' experiences. It is the reasons why self directed options are so good.

Accountabilities

Some of the paperwork around Key Result Areas and the accountabilities are something we can do without. How the monies are spent is fully accountable in line with his plan. I know my son has a purposeful life and purposeful lifestyle. Why do I have to complete this paperwork to justify what we do? We have got the hang of the paperwork requirements, but it is just adds an extra layer of administration – at a cost to me. I would rather spend more time working on my son's augmented communication aids which is critical to meet his needs.

I have listened to Carolyn Tomlinson from In Control in England. They have a debit card which is attached to their funding. This would be a great option so that I can easily cover costs in line with our plan and budget rather than having to seek reimbursement.   A debit card which is linked directly to the funding can still be cross checked. It is a struggle for some families to pay for something and then to get the money back.

Whilst we have a lot of flexibility in how we manage supports, I would still like additional flexibility. Such as being able to access speech therapy. This is something I need for my son, he doesn't talkand we use augmentative communication. Within the guidelines we are *not able to use those types of services, yet that is what we currently need. He is 23 and he does not fit into the demographic of a lot of services now as he is over 18. These are the sort of things I find intensely frustrating in caring for him at home, it is not recognised that this service has not been provided…trying to access these services here, I am on a waiting list with three year olds that have been on the list for a year. What is going to come first, early intervention or a 23 year old? If only the parameters could be pushed to each families circumstances. Everyone's circumstances are so individual. You have a young man who is getting more and more frustrated because he cannot express himself, but he understands. I am in an isolated area in the south coast which has limited services anyway. Those sorts of things around the wording. It would be nice to see a little bit of flexibility, so that we can provide him with what he needs, when he needs it. Something basic like communication is important. I would like to see a more holistic approach to meeting his support needs. We could use some of his existing resources if we were able to do this.*

Positive outcomes

We are very happy with the way it works, it is just divine. . My son has a beautiful blend of informal, formal and bought services, and it changes all the time and he calls the shots.

It is so nice to not be locked in, because you are already locked into being a carer. This is not locked in, it gives you the first bit of freedom, where your life has been decided for you, as a carer, there aren't people deciding how your son should be treated or where he should go, that in itself is the quote…it is right down to "choice". He knows, he has learnt in the last two years, he can go to his communication board and say, I don't like, I don't want, and it will change. Not me going, sorry sweetheart, there is nowhere else for you to go. I am watching my young person have an ever evolving life, as he should.

Holistically meeting needs

We would really like to be able to manage our respite each year in line with a self directed option. This way we could employ people who know my son and we can organise respite so that we actually get a break. I have been fortunate that a local provider employed one of my staff so that my son could go away for a three day weekend as part of a program. It was fabulous. He had the best time. It is the first time that he has gone away. It worked so well. He came home relaxed and happy. Our worker had trained up some of the other workers on the skills that you need to work with him. They are such great benefits. They are the sort of things that I am looking at and thinking, we are making this happen through self directed options and through gentle nagging and saying that is not good enough. We need people who are familiar with our son, for him to have a positive experience, otherwise there is no point in sending him as the behaviours when he comes home are just atrocious and then that makes our life more difficult.

Being able to incorporate any of his respite dollars that he already attracts and being able to self manage them, that would be fabulous. Same with accommodation which we are starting to think about. We want to be able to have supported living options that we direct.

We currently have access to respite. Being able to manage this ourselves would make much better use of the resources and actually meet our needs. I relish the opportunity to apply the same principles to respite options. I currently have access to HACC in home respite. . I am finding that in home doesn't suit us, it doesn't suit my son, it is so inflexible. They cannot pick him up, they cannot take him anywhere, so I have to get community transport as well. I end up with two or three services coming to do the one thing. It is such a waste of resources, which is my frustration. y streamline everything with self directed options, cut out all that two or three lots of people are doing mileage, paperwork, admin. It is just such a common sense approach. I envisage one day when you look at my son and the respite that he currently attracts, what sort of respite he needs, what is the respite needs for the family, providing an hourly or dollar allocation per year and then choosing how to use those resources to meet all our needs. The respite is a big one. We have Sams' lifestyle beautifully covered. He has a great life. But ours as a couple still has not been addressed through respite. I think having a more flexible model, where it is not restricted to in home and where my son isn't wondering who is coming and who is going. . He finds it too confusing. It could work a lot better and I imagine it would work a lot better where we could also manage our respite dollars.

In the Future…

I envisage the path of transition which is one we have started on already, the transition from home. That is why he goes to the respite house once per fortnight, he spends one night there. He has never left the family home until last year. That is the beginning of the transition. I have just had a home modification done in our garage where he has his own room with a kitchenette and he has his own front door, so that services will be attracted to him and not to me. That is stage 2 of his transition.

Stage 3, I envisage will be in the next four or five years when he moves into his own place. That is the plan I have. My dream is to see him settled happily with people of his own age and our choice and in a situation that I have a sense of control over. He will still spend time with us and extended family. My son is a very vulnerable young man and cannot talk, so I need to physically see him often to see that he is okay. That is my dream - feeling satisfied and secure in that he will be okay in a safe, secure and sustainable home. I would want this as a self directed option.

We are working with a couple of other mums whose young people are a bit older than my son. We are really just gathering as much information as we can at the moment, on different options, on housing, different ways to go about it.

We get little funding down to this part of the coast, none for accommodation in the far south coast. I am trying to get us as a blip on the radar. We are still doing our research around accommodation, and we have a few younger mums coming on board who have identified that they need to start thinking about this now. We are still working out how to get there, we know where we would like our young people to live, we know roughly with whom. .

There is a very proactive group of young mums who would like self directed options now, with the funding that they are getting and the money that the kids have at school. They would like to have some control over who works with their young person in school and in respite. It is fascinating watching it become quite contagious.

I listened to two wonderful speakers when my son was two years old, so twenty years ago. Marsha Pearpoint and Jack Marshall, they were from Canada. They spoke about that exact model – individualised. That is my frustration; these ideas have been around for so long, why aren't they picked up and run with? This is my complaint now to the politicians, stop the rhetoric and just give it to us. Make it happen. Where there is a need, provide individualised support. We are so behind!!!

Safeguards in the future

We have a "mini board" set up for my son with three of his siblings, one cousin and an independent family friend. Three out of the five will need to decide a yes vote before any monies can be spent and major decisions made. It is in its early stages. We are planning to hand over before we are not around to care for him anymore.

I have begun a private blog on all of my son's care needs and this will grow and be updated constantly to reflect his complex needs, communication style, health, medications, specialist appointments, current lifestyle etc. The biggest safeguard I need is accommodation for our son in our current life – NOT our afterlife!!

5. Eric's Story

Background

Eric is now 22 years old and is one of two siblings who have a disability. Eric has high support needs. We manage our own support with secondary and financial intermediary support. His funding covers the equivalent of four full days. His week includes:

- *Running his own business as a tidy up service within his local community;*
- *One day of gardening employment at a local nursery;*
- *One day at a centre based day program where he meets his school pals; and*
- *Once a month having a date night on Saturday night with his girlfriend.*

We would like to have the option of direct payments and then we can have complete control over and negotiate the cost of insurance, pay roll etc. As his Mum, I have the skills and *expertise that I could manage our funding and could purchase and pay for support and services we needed or did not want to do ourselves.*

Supported Living Options

We are planning for Eric's future which we are envisaging will be a mix of formal and informal supports. We have clear ideas about what this will look like and want to be able to organise this ourselves. We think that we can achieve this at less than the cost of a group home placement and to meet Eric's high care and support needs.

Inefficiencies and lack of flexibility

We are most frustrated at the present time of the incapacity of the service system to deliver flexible respite options (and we have not yet imagined how our dream for supported living will come to pass). This year Eric had a small flexible respite option allocated to him. We have been seeking to manage this funding through a self directed option. This has not been possible and we went through the following:

- *Individual respite allocation is held by the service provider. The service provider completed an assessment in our home to enable it to broker the service. We identified how we wanted the respite resources to be allocated and the worker. This was not taken up.*
- *The brokered provider also came to complete an assessment in relation to providing respite services. Again identification of how we would like resources allocated and the worker identified.*
- *Finally we were able to organise for the 'flexible respite' to be brokered as per our existing self directed option, so that we could employ a worker of our choice and manage Eric's flexible respite.*

The end result for us was positive, however, it took multiple assessments. This is inefficient in terms of the cost of this, and also in terms of my time as his Mum and my lost work time to be present for multiple assessments. This is funding that was allocated to Eric. We are hoping for arrangements to be much more flexible, portable and optimally direct to us.

Part Two:

1: Productivity Commission issues: Who should be the focus of a new scheme?

This section addresses the fundamental issue of who should be in receipt of the resources that are generated from a NDIS, and administered through the new 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.

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.

1.1. **Principles** - In Control Australia supports the principles agreed to at 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. In Control Australia 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. In Control 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.

1.2. 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 the block-funding of services, to allow 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.

1.3. 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. In Control Australia 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.

1.4. 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 1.5 to 1.9.

1.5. The term “severe and profound disability” is a statistical construct, which has application to disability policy eligibility and service determination because 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 not validity as an eligibility criterion; and it 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.

1.6. In Control Australia supports the recommendation that the 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).

1.7. In addition members of In Control Australia were involved in the process of development of the International Classification (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.

1.8. The submission analyses the spread of current supports for people with disability in Australia, and concludes that there is comparative information, and relatively good targeting in relation to the three activities of self care, mobility and communication. However this represents 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.

1.9. In Control Australia supports the comments about the dichotomy between "disability" and "non-disability" being a false one, when in fact everyone in the population experience 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). In Control Australia 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 an strategy to enable the person with disability to become more independent, and achieve their goals of inclusion and participation (this point is developed further at 3.4).

1.10. This section to date 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.

1.11. 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 In Control 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. However, we also 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.

1.12. 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, but robust strategy to quickly enable people in these groups to obtain the same levels of support as is available to others in Australia.

1.13. 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.

1.14. 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.

1.15. 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.

1.16. 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

2: Productivity Commission issues: What should a new scheme cover?

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

1.17.1. In Control Australia 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.

1.17.2. 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 Part One: 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.

1.17.3. 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.

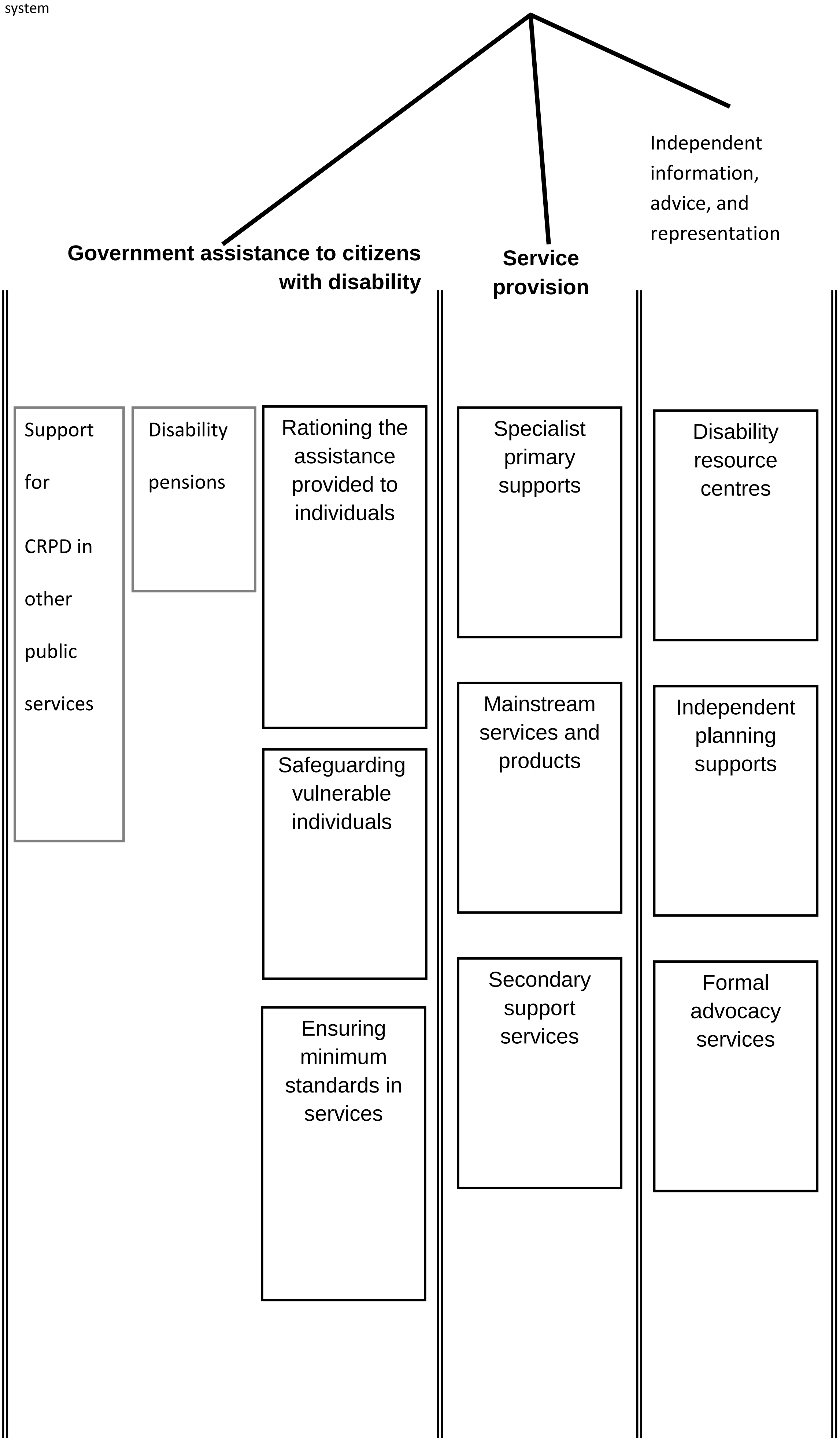
A central system with overarching responsibility is required. However, there needs to be flexibility to build on the strengths of local responses and initiatives. This is a fundamental strength that needs to be in place.

- **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 Part One: 2.3.4. 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



1.17.4. 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.

2.1.5. 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.

2.2. 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:

- 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.

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

- 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.

- 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.

- 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.

2.3. Roles and responsibilities in a new suppor 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 require 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 assist 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.

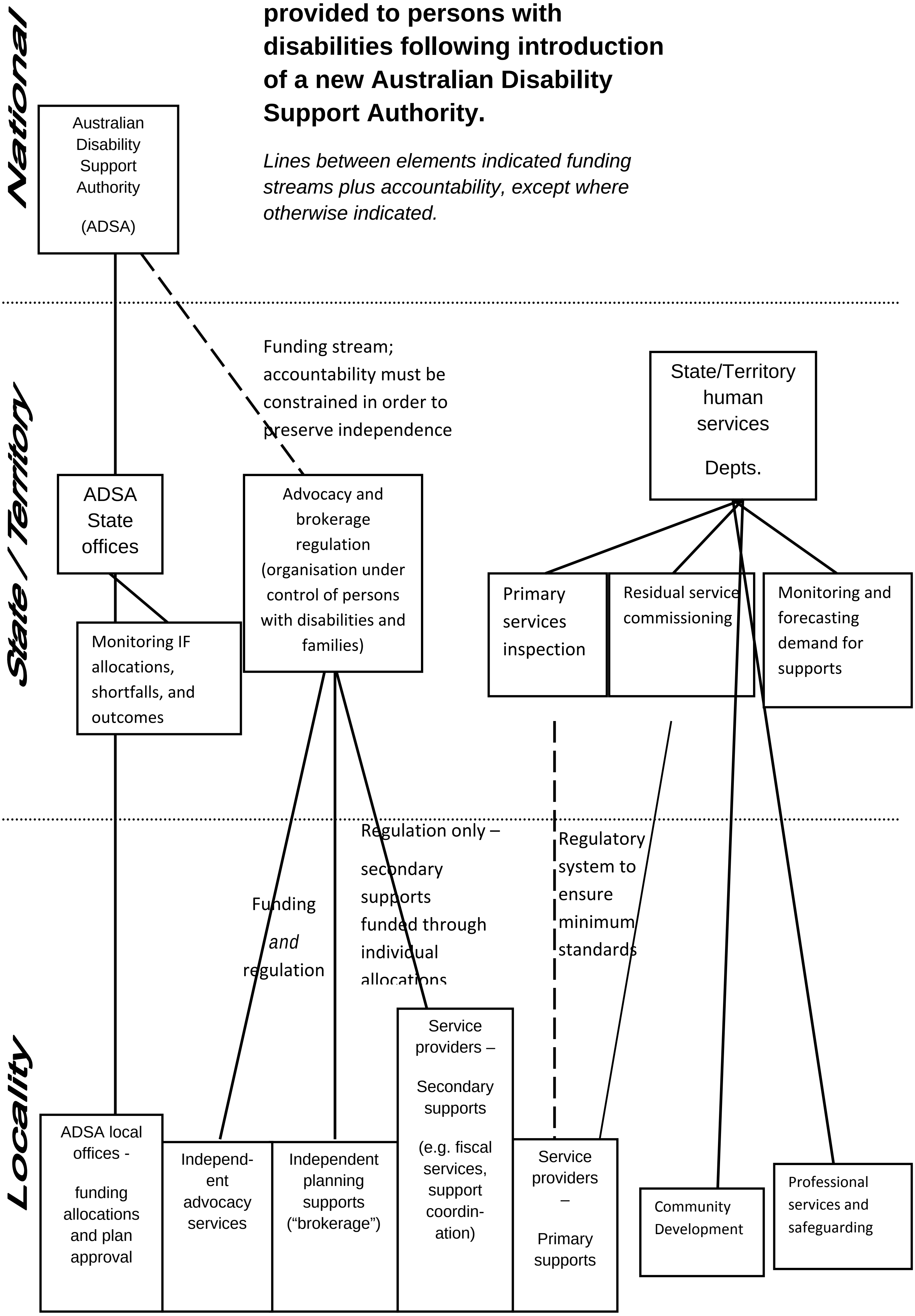
C6 Act on behalf of persons with disabilities and families to make representations to local, state, and new national service levels on the operation of the new service. For example in the level of funding, criteria for approval of plans, and the operation of the local systems to approve plans submitted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



2.4. Types of services and supports

2.4.1. 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.

2.4.2. 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, eg. 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.

2.4.3. 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

2.4.4. 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.

2.5. Discussion regarding risks of new scheme

2.5.1. In Control Australia 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 (see Part One: Literature Review). 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.

2.5.2. 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.

2.5.3. 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.

2.6. Safeguards (see g) Safeguards)

2.6.1. 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.

2.6.2. 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.

2.6.3. 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.

2.6.4. 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.

2.7. Resourcing the Sector

2.7.1. 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.

2.7.2. 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.

2.7.3. 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.

2.7.4. 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

3: Productivity Commission issues: How much funding? Who decides this?

3.1. 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.

3.2. In Control Australia 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 (see Section 1). In Control Australia 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 timebeing we are happy to endorse the proposals put forward by the Workshop Participant Group who 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. Eg. 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.

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

3.3.1. In Control 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, In Control 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. In Control 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.

3.3.2. 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.

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

Firstly, a gatekeeping process, to determine:

- whether the need for assistance arises from disability (as understood by the guidelines for eligibility outlined in Section 1); and
- 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.

3.3.4. 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 disability 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.

3.4. Unpaid support from family members

3.4.1 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 disability and the expectations placed on carers.

3.4.2 If funding is calculated on 'net' support needs, it will trap people in their existing arrangements. The adult with disability 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.

3.4.3 When the person with 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.

3.4.4.We recognise, however, that Australian society has long presumed upon the families of adults with disability 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 responsibility that may initially be 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.

3.5. The Support Plan

3.5.1.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 Plan[1]. 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.

3.5.2.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.)

It is possible to establish workable criteria that bring together the wishes of the individual, and the requirement to fund appropriately and have suitable accountability for funding on the part of the funding authority. Suitable criteria have been developed and tested in other jurisdictions, for example the seven criteria developed by *In Control* in England (reproduced below)

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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: http://www.in-control.org.uk.
	The plan must set out how you want	The plan should say how you will use your	The plan will not be agreed if the plan

4. How will you spend your Individual Budget?	your Individual Budget to be used. 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.	money. You can have your Individual Budget as a direct payment, 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.	does not say how your money will be used. If you are taking your Individual Budget as a 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 about what decisions you will make. Where other	The plan should describe the decisions that you will be making, and those that others make. If someone else is	The plan will not be agreed if it looks like others are making decisions for you if you could reasonably make those decisions

	people make decisions for you, it has to be clear how they involve you and get your agreement.	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.	yourself.
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.

This is just an example, but one which has been able to be readily adopted by local authorities in the UK.

3.6. Assessment of risk – individual arrangements

3.6.1.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.

3.6.2.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.

3.6.3.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.

3.7 Building capacity for people with disability and services

3.7.1 Engagement of people with disability and those close to them is fundamental to the development of individualised funding. Development of information, and skills, including training, is needed for effective support planning and leadership. People with disability and their allies require resources and confidence to develop and implement support plans, direct their own services. They also need the capacity to partner with peers and organisations to improve the supports they receive.

3.7.2 Early establishment of processes to facilitate review of personal circumstances will be required to provide confidence the system will provide flexible options when needed.

3.7.3 Importantly, service users and other people with disability will need information about the funding options available, as well knowledge about the potential uses to which funds may be put.

3.7.4 Educating people with disability and families about the funding options available, processes to acquire funding and options and opportunities of how the funding can be used.

3.7.5 Support for the implementation of person centred planning into existing disability service organisations is necessary to foster the cultural shift required to move the locus of support from the service provider to the customer. Establishment of an a new national disability support system featuring individualised funding will be assisted through development of resources and systems to develop person centred support plans utilising standardised support costing and service planning tools and templates.

3.7.8 Skills development is also required for Individuals who are to facilitate or broker support (see Part One: 2.3.4 for details).

3.8 Ensuring the implementation of person centred thinking skills in service delivery organisations

3.8.1 Through the transition period it is important to support individuals within organisations and the wider community so that they can champion, coach and mentor people with disability person and service providers in person centred approaches, which in turn support the cultural change required. .

3.8.2 Training for service providers which comprises staff, management and boards is needed to embed a culture of person centred approaches, in particular individualised support planning. This might be facilitated through Action Learning. Action learning is a process in which action plans for change are developed as a result of what has been learned. Action Learning groups should be led by people with disability and include families, service providers, government and interested members of the wider community.

3.9 Service Evaluation

3.9.1 The ADSA should encourage service to evaluate services provided to people with disability need to be based on holistic outcomes achieved and on customer satisfaction with the services provided. People with disabilities and families should lead service evaluation processes. Service evaluation and accountability system s should be easy to understand using simple English.

4: Productivity Commission issues: How should the scheme be governed? By whom?

4.1. 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.

4.2 In Control Australia 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 4.1 above.

4.3 In Control is primarily focused upon 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 families and carers of people with disability, at all levels of decision-making.

4.4 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.

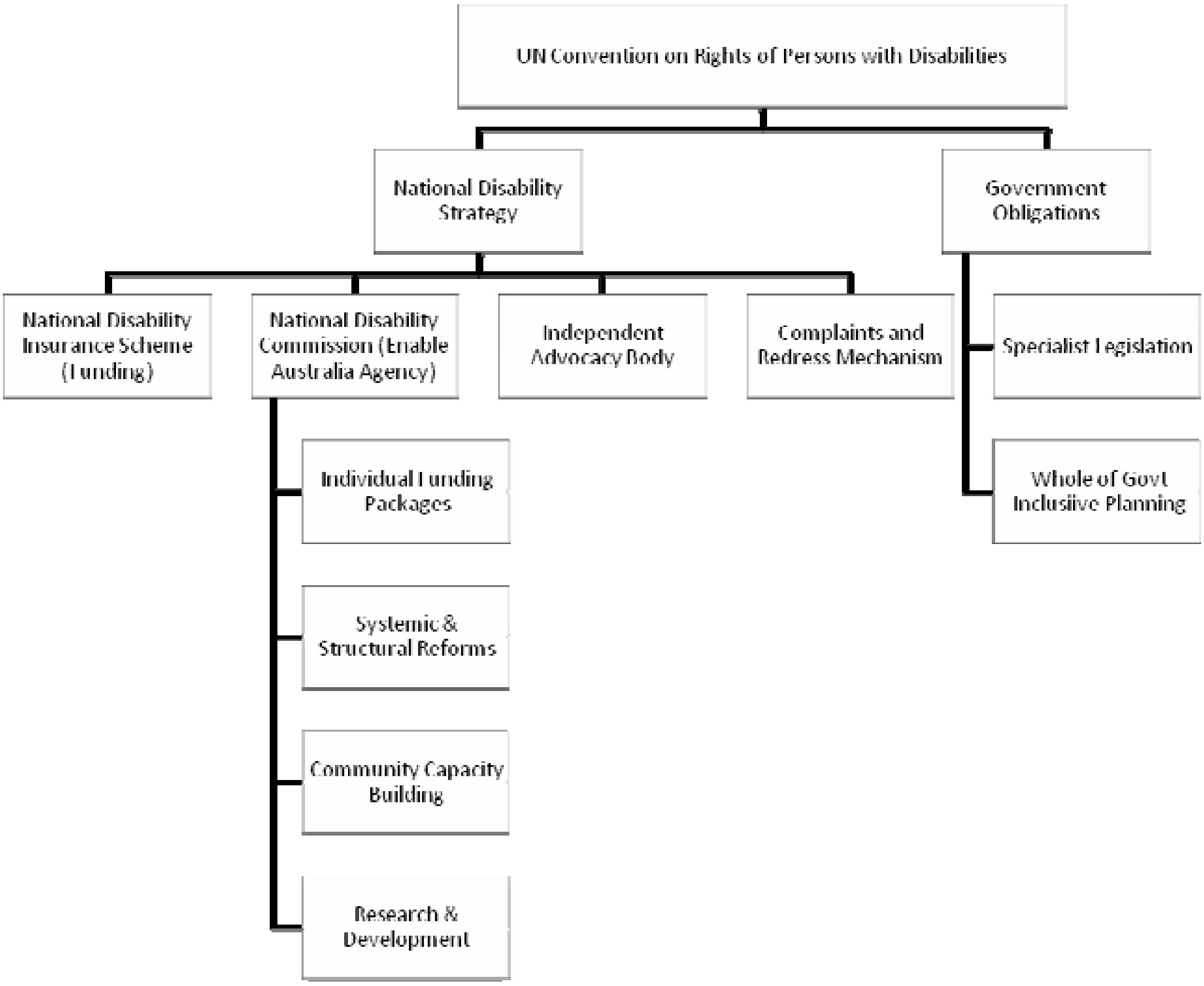
4.5. The authority must ensure there are mechanisms for local decision-making by the advisory groups of people with disability, and families and carers of people with disability, in particular to contribute knowledge and expertise about local conditions, gaps and resources, which need to be taken into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

4.6. 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.

5: Productivity Commission issues: Where does the proposed scheme fit with other government responsibilities to support the full inclusion of people with disabilities?

5.1.In Control Australia firstly endorses the position taken by the Working Group, in response to this issue. The Working 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.*

  (Please note that the different terminology used in this diagram has not been amended to reflect the language used by In Control's submission, in order to protect its integrity)

5.2. Section 3.3.1 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, In Control 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).

5.3. In Section 1.1 we have identified the need to include in the new scheme people with psychosocial disability, who are eligible on account of their support requirements. In Control Australia 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, In Control Australia 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.

5.4. 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.

5.5. 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.

5.6. 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.

5.7. 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.

References and acknowledgements

(A full reference list from the literature review is available at the end of the review in Part One.)

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