Submission made by Julia Farr Association

A National Disability Strategy for Australia

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1.0 PURPOSE

The purpose of this submission is to inform the Australian Government about ways in which a National Disability Strategy can ensure that people living with disability[1] are active citizens in the community and are supported in ways that meet their individual needs and circumstances.

2.0 INTRODUCTION

The Julia Farr Association (JFA) and its predecessor organisations have been involved with the disability community for 130 years. The organisation holds that the following values should inform policy development in this area:

- Personal authority – where people living with disability have and exercise control over the decisions in their lives;
- Social inclusion – where people living with disability are included as active citizens in the life of the wider community;
- Capacity-building – where people living with disability, through access to experiences and support, are growing their capacity to enjoy active lives of choice. This also includes the wider community growing its capacity to be inclusive and supportive of people living with disability.

JFA is not a service provider, nor an advocacy agency, has no political affiliations, and is not Government-funded. As such, we feel we are in a good position to offer comment and analysis without vested interest.

JFA, through enquiry and networking in the disability community and the wider community, seeks to foster innovation, share useful information, and identify and promote policy and practice that may be helpful in improving the life chances for people living with disability.

JFA sees the development of a National Disability Strategy as an important opportunity to create the basis upon which people living with disability can access supports and services so that people get a fair go at active citizenship.

3.0 THE PROBLEMS TO BE ADDRESSED IN A NATIONAL DISABILITY STRATEGY?

JFA believes that the proposed core outcomes of the National Disability Strategy (which focus on people living with disability being provided with opportunities to actively participate in the community and make choices about how they want to live their lives, as well as families and carers receiving sufficient support), provide a

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[1] Note that throughout this document we use the term people living with disability, and we acknowledge and support the benefits that family member can also gain from the arrangements we argue for.

strong foundation upon which more defined objectives and actions must also be established.

JFA has identified through qualitative research[2] a range of barriers within human service systems that prevent people living with disability from achieving such important outcomes. Some of the key concerns are:

- A lack of choice in regards to the support services currently available[3] [4];
- The limited capacity of service providers to respond to the needs of people living with disability due to the restrictions placed on them by contractual frameworks[5];
- Too much time taken by the system to respond to the needs of people living with disability[23] resulting in situations where people's 'needs have changed such that the response has become less relevant to their current needs'[6] ;
- People in the system who make decisions about the supports provided to people living with disability 'are too-far removed from the point of need, which makes them particularly reliant on the overly-filtered information they receive from the system'[7];
- A lack of flexibility and willingness by the system to think outside the square and 'a lack of long term planning that provided context to the supports asked for, and how they can be delivered in ways that are helpful to the goals that people have in their lives'[8]
- A lack of physical access and access to opportunities such as education, employment[9].

JFA believes that such barriers need to be addressed as part of a National Disability Strategy to ensure that people living with disability are provided with opportunities to make genuine choices about the supports they receive. There needs to be a strong focus on the delivery of flexible, responsive and individualised support mechanisms.

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[2] JFA qualitative research with people across the South Australia disability community has included feedback from over 400 people who attended our *Loop* Conference in 2007 and 2008, and input from the tell us survey, where over 780 people provided information about their experiences living with disability issues.

[3] Julia Farr Association 2008, 'tell us survey – Draft preliminary report', Julia Farr Association, Unley, South Australia.

[4] Julia Farr Association (expected publication in early 2009), 'Imagining better in our communities. Reflections from the Loop 2008. Getting a good life: Taking control of what's possible', Julia Farr Association, Unley, South Australia.

[5] Williams, R 2008, *Why is it so hard to speak up and be heard? Views from the Loop conference 2007*, Julia Farr Association, Unley, South Australia.

[6] Ibid, p. 12.

[7] Ibid, p. 12.

[8] Williams, R 2008, *Why is it so hard to speak up and be heard? Views from the Loop conference 2007*, Julia Farr Association, Unley, South Australia, p. 13.

[9] Julia Farr Association (expected publication in early 2009), 'Imagining better in our communities. Reflections from the Loop 2008. Getting a good life: Taking control of what's possible', Julia Farr Association, Unley, South Australia.

We refer you to *appendix A* detailing further information from *The Loop 2008* conference, where participants responded to the question 'If you could imagine something better for people living with disability in your community, what would it be?'

4.0 RECOMMENDATIONS

We submit the following recommendations that will support people living with disability to actively participate in decisions about their lives.

- ***Introduce Self-directed Funding packages for people living with disability***

  Such funding arrangements provide people living with disability with the flexibility to respond to their individual needs and circumstances through having full control over the decisions about the support they receive. This can have 'a positive impact on quality of life, as reflected in areas such as making choices, achieving goals, participating in the community, and growing relationships'[10]. JFA believes that such benefits demonstrate how Self-directed Funding can play a major role in achieving the proposed outcomes of a National Disability Strategy. Attached as *appendix B* and *appendix C* are two monographs that give further information on the reported benefits of Self-directed Funding and considerations for its implementation[11].

- ***Establish proactive 'front foot' planning arrangements that focus on supporting the strengths and capacities of people living with disability***

  Such arrangements should have the following characteristics:

  - The plan should be proactive so that people don't have to wait until their lives are in crisis before something happens;
  - The plan should recognise and build on the strengths and capabilities that people have;
  - The plan should take a broader view of the person's life, beyond personal care, equipment and therapy, and into areas such as employment, relationships, voice, belonging and aspirations.

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[10] Williams, R 2007, *Individualised funding. A summary review of its nature and impact, and key elements for success,* Julia Farr Association, Unley, South Australia, p. 19.

[11] The monographs are titled: *Individualised Funding.. A summary review of its nature and impact, and key elements for success. General Considerations on Implementation*

JFA believes that through focusing on proactive and strength-based individual planning, human service systems will be more effective in their response to how people living with disability wish to live their lives.

- ***Investment in community capacity***

  In addition to the allocation of disability support funding to individual people via self-directed funding, we believe that Government should make a separate investment in growing the capacity of communities to be properly inclusive of people living with disability. This can include for example:

  - Establishing mechanisms that make stronger demands on government and community organisations in terms of participation in organisational decision-making by people living with disability;
  - Proper investment in the generic training of professionals such as
    - Teachers,
    - Architects, town planners and other building industry personnel,
    - Transport industry personnel,
    - Health and community service professionals;
  - Raising awareness among employers across all workforces, on the benefits of workplace diversity and the intrinsic value of employees with disability;
  - Greater connectivity between federal, state, territory and local government planning and services, so that there is a greater coherence and cohesion in the development on truly inclusive communities;
  - Arrangements to ensure that all new building work, including renovations to existing buildings, conform to clear accessibility standards;
  - Training to disability support staff to ensure that they support people living with disability in ways that honour and reflect the person's dignity and uphold the person's personal authority;
  - Development of a new approach for promoting the disability sector as a valued career choice, to successfully attract those people most likely to uphold the values of personal authority, social inclusion and capacity-building
  - Government investment in services that build inclusion, rather than investing in services that 'train' people and their families to be excluded and separated. For example, when families first learn they have a child with disability, the focus of Government funding should be on family capacity-building and community inclusion, and not for example having separate pre-schools for kids because they happen to have been labelled autistic.

- ***Accountable action in support of achieving positive outcomes for people living with disability***

  JFA believes that in order for the system to become more responsive to the needs of people living with disability, a National Disability Strategy needs to focus on mechanisms which support the system to measure and monitor the extent to which their needs are being met. A theme which emerged from *The Loop 2008* conference was the lack of ongoing measures to check that funded disability organisations are providing the services they claim to provide and the extent such services are useful to people living with disability[11]. There needs to be clear outcome-based measurements in service agreements to ensure that providers are properly accountable for assisting people living with disability to make genuine progress in terms of personal authority and active citizenship.

- ***Provision of inclusive services within society***

  All services across the government, commercial and community sectors should be inclusive and accessible to people living with disability and this should be enforced via effective legislation.

5.0 CONCLUSION

JFA believes that these recommendations need to be considered as part of the National Disability Strategy as they will provide people living with disability with increased opportunities to exercise full control over their lives and participate fully in their community as valued members of society.

Thank you for the opportunity to make this submission. We welcome the opportunity to have further input to the drafting process, and can meet with you at your earliest convenience. Our independence, our information resources, and our ongoing dialogue in the disability community, all mean we can assist you to build a truly effective National Disability Strategy.

For further information about this submission, please contact:

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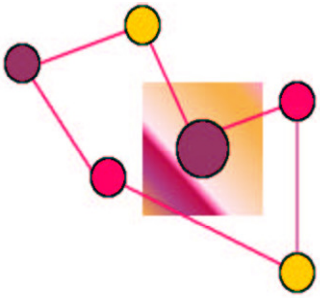
Appendix A

Reflections from The Loop 2008 Conference

DRAFT PUBLICATION
Not authorised for wider circulation

Reflections from *The Loop* 2008



GETTING A GOOD LIFE:
TAKING CONTROL OF WHAT'S
POSSIBLE

imagining better in our communities

1.0 INTRODUCTION

The Julia Farr Association ran *The Loop 2008* Conference from 13 October to 25 November 2008 at a range of different venues around South Australia. The intended emphasis of *The Loop 2008* was to ‘talk with’ people, not to ‘talk at’. The essence is a conversation between all participants, including the presenters. Over 200 people living with disability, families, carers and others from the disability community attended the conference.

The Loop 2008 visited Mount Gambier, Murray Bridge, Loxton, Clare, Whyalla, Port Pirie, Port Lincoln, Victor Harbor, Kingscote and Adelaide.

The theme for *The Loop 2008* was ***Getting a good life: Taking control of what’s possible***. One of the questions participants were asked to discuss was: If you could imagine something better for people living with disability in your community, what would it be? Below is a summary of some of the suggestions and comments made by participants.

2.0 RESPONSE TO QUESTION: IF YOU COULD IMAGINE SOMETHING BETTER FOR PEOPLE LIVING WITH DISABILITY IN YOUR COMMUNITY, WHAT WOULD IT BE?

Suggestions were primarily provided by participants in regional areas highlighting a number of common themes which focus on ways the current system can provide opportunities for people living with disability to have greater control over how they live their lives. These common themes include:

2.1 The Service System needs to:

2.1.1 Fund and provide more services

- More respite services (in and out of home and for school aged children)
- Local services so people don’t have to travel to Adelaide
- More recreational services
- Funding local solutions that are right for local people
- The need for more funding for services

2.1.2 Focus on whole of life

- There is a large gap between youth and aged, ie the middle age group falls through the gaps
- Redesign the system to allow for change/deterioration
- Consistency of services from birth to adulthood
- School – post school. Get in early to assist people to think beyond school

2.1.3 *Provide the right information and support*

- Central reference point to learn what is available
- Misleading information therefore there is a need for effective source of information which leads to positive outcomes
- Services under one umbrella
- One stop shop
- Better links of information regarding the pensions especially regarding kids at 16 years of age
- Access to information about what is possible

2.1.4 *Be more responsive to the needs of people living with disability*

- There needs to be a real awareness at the top, of the reality at the bottom of the chain
- “Too many chiefs, not enough Indians” – flatter structure
- Government should look at what happens elsewhere (we are out of step with human needs in modern society)
- Most departments don’t provide the service they state they will
- We need to fix things so that people don’t have to reapply or keep demonstrating their disability
- Systems to re-evaluate expectations of people with disability
- Strengthening the attractiveness of the disability support industry (workforce)
    - Need younger people to come into the industry
- Stability in leadership within Disability SA and more avenues for feedback/good evaluation processes: “Why no stability?”
- Raising employer awareness of benefits of a diverse workforce – so that people living with disability can get open employment

2.1.5 *Improve communication and relationships within the system*

- Need for good structures in place, and better communication between organisations
- Less competitiveness between agencies
- Much greater interrelationship between all agencies, all states and levels

2.1.6 *Create a governing / independent body to support the system to be responsive and accountable to people living with disability*

- Governing body to oversee the standard of care or an independent body
- Create a Disability Ombudsman

- The voice of the disability community direct to politicians, not bureaucrats, eg regular human interest stories

2.2 The processes available to support people living with disability need to:

2.2.1 Be responsive

- The length of time for approval of service provision is a concern
- Faster response
- Easier flow into the system
- Remove red tape bureaucracy
- Listen, including to what people don't like
- Disability SA staff to become specialised in particular fields, eg transport, individual funding, accommodation, social and recreation needs, employment
- Recruiting people with 'the right stuff' (attitudes and values)
    - Every young graduating professional do a tour of duty in the country
- Supported decision-making
- Open communication
- Empathetic services and their employees
- Provide meaningful options for people in the community

2.2.2 Be accessible

- Easier access to equipment
- Transport – affordable, accessible and sufficient
    - Promotion of what is out there, eg Disability Transport Scheme
- Standardised approach to access

2.3 Building capacity within communities through:

2.3.1 Giving people living with disability a voice

- Using mentors with "life experience" not just someone who is managing the system/process
- Reliable advocacy
- Quality parent representation
- Finding a trusted other
- More volunteers to assist
- Up skilling carers and loved ones
- Strong, connected local community
- Support families to stay together

- Continuing education
- Give people with a disability double vote at election
- Create a buddy system
- Show people what is possible

2.3.2 Raising community awareness about people living with disability and the contribution they can make to the community

- Disability awareness day
- Raising community awareness, eg buddy systems in schools, inclusive
- That people actually look at what people with a disability bring to the community / valuing potential
- Need to focus on “what is going right” or what gifts (abilities) individuals have
- Need for consumer education to stop “being taken advantage of”, eg mobile phones, home loans
  - Through informing retailers of people’s rights
  - Through informing people living with disability of their rights
- Accountability for the whole community

2.4 An Individualised Approach focusing on:

2.4.1 Individualised Services and Choice

- More choice to services and lifestyle
- Work place choice/options
- Less overheads, more direct support
- Keeping our independence
- More services that treat people as individuals – “meet them where they are at”, including better individual planning
- Flexibility of Choice
- Style to suit the person, so their voice is heard – individualised
- Being / feeling accountable to the person I am supporting
- Specialist therapies that meet people’s needs, for as long as people need them
- Services built around individuals and their family

2.4.2 Self-directed Funding

- To provide:
  - choice about who will provide support and when
  - flexibility and ability to live life

    - more opportunities to earn money so people can fulfill life goals
- So that people manage their own affairs and direct their own support

2.4.3 Person-centred Planning

- Front foot versus back foot planning
- Advice and support with daily living, eg managing on a budget, skills in cooking etc
- Stand alongside people, being there especially during the scary new stuff and working through the consequences
- Focus on people's strengths and positive characteristics
- Acknowledging ordinary

2.5 Some of the other comments and suggestions provided by participants were:

2.5.1 Accessibility

- Disability seating to be available on public transport
- Reduced waiting time for access taxis
- Change criteria for taxi vouchers
- More accessibility to Adelaide services
- Need functioning pedestrian crossings
- Public toilets – disability access
- Practical walkways, footpaths
- Better access to community venues

2.5.2 Support

- There is a large amount of paperwork to employ a support worker interstate
- Make all senior public service personnel in the disability field become familiar with operational aspects of community houses to understand the limitations
- "out of hours" activities, care, transport, safety, meals, socialising and communications
- Tuning in / being there

2.5.3 Services

- Heated indoor swimming pool
- Better housing
- Better post school options
- Supported accommodation – buildings
    - Choice and safeguards

  - Involvement of community
  - Recurrent costs of support
  - For older people
- Local specialist consumer choices out of Adelaide that up skill local therapists
- How teachers are trained: to include disability

2.5.4 Other

- Carers are valuable
- Find out the number of people in Australia so I can provide or seek funds
- Modern technology enabling
- Booklet on what is available in the South East – broad spectrum of information
- Carers allowance should be higher – at least double it
- Social inclusion

Appendix B

*Individualised Funding-
A summary review of its nature and impact, and key elements for success*

julia farr

association

individualised funding

A summary review of its nature and impact, and key elements for success

robbi williams

Individualised Funding

A summary review of its nature and impact, and key elements for success

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This article reflects the views of the author, and does not necessarily reflect the views of the above persons, or the publishing organisation, Julia Farr Association.

Foreword

At the end of 2005 I responded to a request to write an opinion piece for Australian disability magazine, *Link*. The topic was *Individualised Care Packages*, and I was asked to offer my perspective as the head of a large service provider organisation.

The resulting article, which appeared in the April 2006 issue of *Link*, carried my personal 'gut feeling' thoughts on the topic.

This current paper offers a more extensive analysis, hopefully enhanced by a more thorough examination of what is known about Individualised Funding, and how it has fared elsewhere.

1.0 Summary

This paper offers an overview of work in various places around the world, where people living with disability and their families have control over their support funding.

The paper describes the basic elements that currently feature, together with the benefits that have been reported, with due acknowledgement to some of the challenges associated with these frameworks. The paper sums up a range of elements that favour success, and concludes that Individualised Funding should be a standard option in all disability support jurisdictions.

2.0 Introduction

Disability policy in Australia is currently limited in the extent to which it gives the opportunity for people living with disability and their families to purchase their own support services. This limitation, in turn, may be contributing to the maintenance of service systems that are driven by what service provider agencies choose to supply rather than by what people and families actually want.

The purpose of this article is to provide an overview of the nature, extent and benefits of Individualised Funding, together with the elements that will support its success.

The article aims to inform key stakeholders – people living with disability, their families, service agencies, and federal and state policy-makers and funders – about the main characteristics and effects of Individualised Funding, so that there is an increased likelihood of Individualised Funding being made more widely available to Australians living with disability.

3.0 Definition of Individualised Funding

First, it is important to clarify the nature of the topic. There are a range of different terms used to describe a shift towards greater control by the person living with disability in the services they receive. Terms include ‘individualised care packages’ ‘individualised support packages’, ‘self-managed care’, ‘individualised budgets’, ‘Individualised Funding’, ‘direct payments’, and ‘cash and counselling’.

In part, this is because there are a number of different methodologies that have technical differences to each other. Many of those differences relate to the extent to which the person living with disability has control over the range of transactions associated with the planning, brokerage and management of her/his support needs.

However, the underlying themes are common, and relate to the advancement of self-determination. For the purpose of this article, I will use the phrase Individualised Funding and will be looking at those approaches where the person with a disability has a significant degree of control (either directly themselves or through a significant other) in how funding is spent. Put simply,

> “Individualised Funding gives control of the funds to the person so that they can purchase the services they require”
>
> *Laragy (2002)*

Similarly, the Nova Scotia Department of Health refers to ‘self-managed care’ as:

> “Providing an opportunity for disabled clients to increase control over their lives and enhance their participation in the community by enabling them to actively participate in the development of their care planning and to directly arrange and administer their own support service needs”.
>
> *Nova Scotia Department of Health (2005)[1]*

In this way, the person with a disability assumes full responsibility for arranging and managing her or his support services (Nova Scotia Department of Health, 2005 [2]).

Dowson and Salisbury make important references to strengths and citizenship in their definition:

> “..public 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)*

Marlett (2006) notes that this approach basically turns the user of services into a purchaser of services. This is a dramatic shift in paradigm in terms of power and control. The question to ask is whether there is a compelling case for the widespread availability of such an approach. We can begin to examine this by considering the philosophical basis for Individualised Funding.

4.0 Philosophical basis

Countering the ironic consequences of professional assistance

In the main, disability support service systems have been built around the contribution of professionals, principally via the medical model of disability, where practical benefits to the disability community were largely framed in terms of 'symptom management' and health maintenance.

The professional approach tends to be grounded in a philosophy originating with the Hippocratic concept of 'never do harm'. This has given rise to the notion of 'duty of care' which, as no doubt intended, has resulted in a general culture of caution and risk aversion, underpinned by suites of professional standards.

This then gets reflected in legislative and regulatory frameworks such that professional staff are guided in their practice more by the need to adhere to those frameworks rather than by the need to create arrangements that genuinely afford the person with a disability more autonomy and choice (Polivka and Salmon 2001; Kapp 2000).

Kapp (2000) notes how such frameworks reflect the misplaced fear of exposure to legal risk, and serve to encourage public service administrators and professional service staff to retain tight control of the process and effectively deny people the opportunity to take charge of key aspects of their own lives. This is unfortunate because, aside from the philosophical considerations, there are some clear practical benefits from giving more control to the person living with disability, and the family. As Kapp (2000) notes

> "There is convincing evidence of that it is health promoting for individuals to make personal choices regarding their own lives".
>
> *Kapp (2000), cited in Polivka and Salmon (2001)*

This professional culture of risk aversion has survived the shift away from a medical model of disability support to a broader 'community care' model of disability support, because professional staff (rather than people living with disability) have remained in charge of the key processes of assessment, care planning, service orchestration and administration. If anything, a culture of risk aversion has perhaps intensified because of the view held by some that more things can go wrong in the community compared, say, to an institutional service, because the community cannot be controlled in the same way as an institution. The perception appears to be that people's vulnerabilities are accentuated in a community context.

However, Kapp says outright that it is ethically wrong *not* to extend to people every opportunity to participate in the orchestration of their own support:

> "it should be the obligation of both the public and private sectors to empower the consumer to overcome any informational and/or intellectual shortcomings to the greatest extent possible, rather than to permit proponents of extensive regulation to latch on to those consumer limitations as a convenient excuse or pretext to foreclose consumer options in the name of beneficence".
>
> *Kapp (2005), cited in Polivka and Salmon (2001)*

Indeed, Polivka and Salmon (2001) argue that

> "Any public policy or program practice that qualitatively restricts the capacity of individuals to exercise autonomy because of impairment bears a heavy burden of justification"
>
> *Polivka and Salmon (2001)*

Unfortunately, systems do often restrict such capacity, and it is not unknown for such restrictions to be linked to funding constraints, maintenance of policy bureaucracy, and perhaps the anxiety of political administrations regarding the risk that goes with individual choices. For example, if someone makes a choice that does not work out, and results in unfortunate consequences, this can sometimes be translated in some quarters as the 'fault' of the political administration for not taking care of its citizens, and may in turn be perceived to reduce the chances of that administration being re-elected.

However, to acknowledge that disability support systems are prone to such restrictions would presumably mean that we also have to acknowledge that disability support systems are not set up to primarily add value to the disability community, but instead to preserve value for public service accountants, administrators and political masters.

Interestingly, and as Nermey and Shumway argue, it is the bias towards 'duty-of-care' and how that is then expressed in service design and delivery, that commits a significant disservice to people living with disability. As is often the case with cosmic irony, it seems that good intentions towards people living with disability, when expressed via duty-of-care, can deliver the opposite effect in terms of acceptance and inclusion.

> "The intense over-regulation of programs and the setting of goals and objectives to meet the needs of the human service system more than the aspirations of people with disabilities, have conspired to prevent people with disabilities from truly contributing to the associational life of their communities"
>
> *Nermey and Shumway (1996)*

The professional perspective on duty-of-care may also be influenced by the tendency to see people living with disability as fundamentally different to most members of a community, and therefore not an integral part of that community. Goggin and Newell note:

> "Something is fundamentally wrong with dominant ways of perceiving disability in which disability remains as the hallmark of otherness"
>
> *Goggin and Newell (2005, p25)*

Goggin and Newell chart a range of lifestyle experiences that show that people living with disability have to navigate all sorts of hurdles in order to access practical support, and in most cases this is done via systems controlled by professional staff. These systems tend to be based on the conceptualisation of people with a disability as being different to everybody else. These same systems then serve to set people living with disability apart from community.

In other words, the systems that apparently have been set up to help, instead serve to hinder people living with disability from accessing the decent things in life.

Self-determination

Meanwhile, there has been pushback from the disability community. Doty et al (1996) noted that professional authority was increasingly being challenged by an ethic of consumerism fuelled by the independent living and disability rights movements.

With a similar sentiment, Nermey and Shumway (1996) focus on the concept of self-determination as it applies to disability service systems, defining it as:

> "..an attempt to fundamentally reform both financing mechanisms and basic structural aspects of the current service delivery system"

They go on to identify four principles that underpin the notion of self-determination as it relates to individual support. These principles are:

- *Freedom*, where people living with a disability have the option of using public funds to build a life rather than have purchased for them a pre-determined program
- *Authority*, where people with a disability really do carry meaningful control over a specific sum of public money
- *Support*, with emphasis on both formal *and* informal support networks and on the expectation that the support arrangements include participating in the rich associational life of the person's community
- *Responsibility*, where people living with disability are expected to assume responsibility for not being passive recipients of support but for also contributing something to their communities, like any other citizen.

The effects of the disability rights movement worldwide have been most recently felt with the UN adoption of the Convention of the Rights of Persons with Disabilities. The Convention contains an explicit commitment to the principle of full participation in the life of the community, and sets out expectations of choice and inclusion across a comprehensive range of lifestyle parameters including, in the preamble,

> (n) *Recognizing* the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices,
>
> (o) *Considering* that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them,
>
> (United Nations 2006)

This newly adopted international position provides significant support for a shift to a greater degree of self-determination in the support that people living with disability receive, which logically would include the option of Individualised Funding.

There have been demonstrations of the value that people place in feelings of autonomy and control. For example, in a study of people living with disability in Tampa Bay, Florida, the researchers found that people value highly the extent to which they retain control over the things that happen to them, and perceptions of personal autonomy were found to be closely related to overall feelings of satisfaction about their lifestyle and the support they receive (Polivka and Salmon 2001).

If we are serious about a philosophical underpinning of self determination and the associated principles such as freedom and responsibility, then we have to look at systems other than program-driven ones.

A shift in power, towards partnership and reciprocation

It is difficult for anyone to live a truly independent life. This is because we all carry a certain degree of reliance on others around us. For example, we tend to rely on our partners and families and friends for emotional support, on our employers for financial support, on banks and insurance companies to assist us take care of what we own, on our neighbourhood stores for supplying us with provisions that suit our preferred lifestyles. For all of us, there will be a measure of reliance on others for some part of our preferred lifestyle. And most of these relationships are two-way, where both parties benefit in some way. As Cialdini (1998) notes, this mutual benefit is a cornerstone of society – it tends to be why societies emerge and how they are sustained. Such is the strength of this principle that it gives rise to the behaviour of reciprocation, where as per the old phrase, one good turn deserves another.

The notions of mutual benefit and reciprocation imply an active relationship, one borne of the contribution of both parties. This logically extends to the participation of people living with disability in the wider community. The implied relationship is that the wider community conspires to offer the person living with disability (just like anyone else) the support they seek, and in return the person living with disability (like anyone else) makes a contribution to the wider community, in whatever way is appropriate and achievable in terms of that person's inherent human value and her or his current (and future) strengths. Similarly, if a person living with disability is afforded every opportunity to participate and contribute, then it follows that the wider community will reciprocate in ways that reinforce inclusion.

Unfortunately, conventional societal and service systems, consciously or unconsciously, tend to disregard the potential for contribution by the person living with disability. If in this way the notion of active participation is not upheld, then the person is placed in a passive role of care-recipient, and unable to enjoy the freedom and responsibility that goes with participation and reciprocation.

Individualised Funding supports partnership and reciprocation in several ways. First it offers a partnership between formal and informal networks of support. Informal, or natural, support networks are the foundation for most of us in terms of the lifestyles we lead. Individualised Funding gives the person living with disability the opportunity to orchestrate arrangements that maximise the interplay between formal and informal arrangements. The more that a person (or her/his advocate) is able to build natural and informal networks in that person's life, where people in the person's network and community give freely of their time because of a genuinely felt regard for the person, then the greater the overall network of support the person can access once the paid component is introduced. Put simply, the disability support dollar will go a lot further if its foundation is the natural and informal support the person gets by being part of a community.

Indeed, to accept this means there is an imperative for all service systems to ensure there is a visible and auditable investment in assisting people living with disability to build natural support networks in their lives. A good example of this investment is the approach called Circles of Support (e.g. Neville et al 1995).

Polivka and Salmon (2001) argue there is therefore an *ethical* imperative to create more opportunities for people living with disability to take greater control over the assistance they receive because, through a sense of shared responsibilities, it moves systems away from a culture of dependency to one of *inter*dependency.

5.0 Prevalence of models of Individualised Funding

Laragy (2002) references two projects in the 1970s, one in British Colombia and one in California, which both represented early practical examples of the concept. Since that time, various applications of Individualised Funding have emerged around the world. It is important to equally note, however, that there are likely to be various examples of local flexible funding that go further back in time, and which have given the person and their family some control over funds. This paper focuses on initiatives over the last ten to fifteen years, during which time there has been a growing movement of interest.

Examples of initiatives can be found in Canadian provinces such as Alberta (Marlett 2006) and Nova Scotia (Nova Scotia Department of Health 2005), and in US states like Arkansas, New Jersey and Florida (Frogue 2003 : Phillips and Schneider 2004), and California, Oregon, Michigan and Washington (Polivka and Salmon 2001). The Ohio Association of Area Agencies on Aging (OAAAA 2005), in promoting their own scheme in Ohio, noted that at that time the number of US states running comparable schemes had risen to 31.

There are initiatives in Australia (for example Laragy 2002: Buchanan 2006) and also in European destinations, for example Wales (Stainton and Boyce

2002), and the Netherlands, France, Austria and Germany (Polivka and Salmon 2001).

In England, Glasby and Duffy (2007) describe how a system called Direct Payments emerged with legislation in 1996. Many thousands of people have taken advantage of this option, whereby they received funds directly from their local authority to purchase their own support services. Glasby and Duffy note that more recently the system called Individualised Budgets has emerged, which offers a range of options for control by the person who knows the actual financial value of the budget assigned to them. This is part of a broader movement called Self-Directed Support, aimed at radically re-designing service arrangements so that they are a better match with the needs and aspirations of people living with disability. As Glasby and Duffy note,

> "Individual budgets seem to offer all the advantages of direct payments, whilst also starting to transform the system as a whole"
>
> *Glasby and Duffy (2007)*

More and more local authorities in England are exploring the potential of Individualised Budgets for people living with disability, and more than two thousand people are now accessing the option. This is in addition to over fifty thousand people who are accessing Direct Payments.

Such has been the interest that the initiative has moved beyond disability and into the realm of support for older persons (Polivka and Salmon 2201: OAAAA 2005) and mental health (National Mental Health Information Centre 2005).

Much of this work has been driven by the philosophical considerations mentioned earlier. However, especially in the United States, there has also been the practical consideration of service costs. The US's 'managed care' approach to health care places a heavy reliance on people taking out health insurance to pay medical and personal support bills should their health circumstances change. However, there is a growing population of lower income people (destined to grow further as baby-boomers hit retirement, and as more people survive trauma but are left with a permanent disability), where costs of Medicaid and Medicare (the US safety net systems designed to ensure that people on lower income can still get healthcare) are starting to really dig deep and become unsustainable. While Australia does not yet operate a 'managed care' model of healthcare and personal support, the fact is that the 'baby-boomer-retirement' phenomenon is likely to place an enormous financial strain on public resources in health care and personal support.

Given, then, that there are numerous examples of system approaches based on Individualised Funding, the next consideration is how it actually works.

6.0 Practical components of Individualised Funding

Genuine control over the funds

There has to be genuine control over the funds by the person or their nominated advocate. A framework where a funder/provider consults with the person, and then make the decisions about what to provide, is not necessarily Individualised Funding.

For the purpose of this article, 'Individualised Funding' happens when the person, either directly themselves or indirectly through a supporting agency or significant other, has awareness of, and control over, a known amount of public funds and makes decisions about support arrangements that reflect her/his preferences and aspirations.

Infrastructure Documentation

It is important that the intentions of the system are documented, because there are explicit expectations placed on the person living with disability as a self-manager of the support they need, and this in turn has implications for the professional staff and funders that they come in to contact with.

For example, the Novia Scotia Department of Health (2005) has set out the various roles and responsibilities in an unambiguous policy document. The document also sets clear parameters in terms of how the funds can be used, eligibility criteria, philosophy and operational guidelines. Interestingly, Nova Scotia has gone one step further than a policy document, and, in a similar vein to England's Direct Payments legislation, has the Self-managed Support-care Act, passed in 2005, which specifically makes the provision for people living with disability to receive funding directly in order to purchase their own support.

Phillips and Schneider (2004) note the usefulness of translating the policy documentation into a 'how-to' manual, in Florida. However, documentation is only the first component. As Phillips and Schneider note, reading a manual is not always enough to ensure that the person living with disability (or her/his advocate) makes a decent go of Individualised Funding. The availability of guidance and advice from another person is a regular feature.

Support for planning and brokerage

A key feature of Individualised Funding is the availability of someone to help plan and broker the support that will assist the person to build a richer lifestyle. In the US, this role is often called the Facilitator-Broker and it implies two main functions. The first, *facilitator*, refers to the process of assisting the person to identify her/his range of support needs, and to develop a plan. This can include calling on other people for their particular knowledge of the person, and/or their knowledge of a particular technical issue.

The second role, *broker*, refers to the process of linking the person and her/his funding with the preferred support options. This can include the task of creating those support options if such options do not currently exist.

Marlett (2006) describes the overall role as follows:

> "…advises and assists the person and his family or friends to identify the supports needed, secure the funding resources and to negotiate and set up customised services to the person's specifications."
>
> *Marlett (2006)*

It is important to note that this role is different to the professional 'case manager'-type role often found in disability service systems. The main distinction is that the person assisting with planning and brokerage is primarily there to serve the person living with disability, while the case manager is primarily there to serve the service system. Of course, every professional in a case manager role will say they are there to serve the person, and that sentiment will in most cases be genuine. However, consider the following three questions:

1. Does the professional act as a 'gatekeeper' for the service system, determining the extent of a person's eligibility for services?

2. Does the professional, on average, have only a limited amount of time to give to a person on their 'caseload', because of overall caseload size and the pressure of new referrals coming through?

3. Does the professional mainly place people into existing services?

If the answer to any of these questions is 'yes', then the role the person performs is more likely that of a case manager, because the imperatives are fundamentally different.

While the ‘case manager’ may understandably need to spend much of her or his time processing (which includes the undertaking of professionally defined technical assessments of someone’s support needs) and gatekeeping, the person assisting with planning and brokerage will spend much of her or his time building relationships.

Indeed, Lord and Hutchison (2003), in their examination of the best examples of Individualised Funding models across Canada, the US and Australia, found that the principles of relationship-building guided the work of staff across the projects, because relationship-building is key to the development of informal supports in a person’s life, and, in turn, the presence of informal supports in a person’s life help strengthen wellbeing and community inclusion.

They go further by noting that in some of the projects, the person in the planning/brokerage support role undertakes indirect relationship-building by supporting the person and the family to develop networks. Lord and Hutchison conclude by identifying 7 key functions evident across the majority of the projects they focused on. These are:

1. Build relationships with individuals with disabilities, their families’ networks, and the local community;
2. Provide information about network building, individualised support options, community resources, and direct funding;
3. Help the individual build a social support network (circle, cluster, group, network), that would be willing to meet regularly;
4. Assist individuals, families, and support networks to plan what the person wants, using a strengths-based approach (including for example dreams, vision, outcomes, preferences and priorities), often facilitating network planning meetings;
5. Help individuals and their networks to develop detailed support plans and budgets for submission to the funder;
6. Facilitate community connections in both formal and informal settings;
7. Assist people to find, purchase, or create supports that may be required and provide ongoing implementation support.

All 7 functions have relationship-building and networking at their heart. This is consistent with the findings of Western Australia’s Disability Services Commission who, in a 2003 review of the Commission’s Local Area Coordination model, reported that the strengths of the scheme included the emphasis on relationships and building informal supports.

Phillips and Schneider (2004) conclude from their research that it is possible for people with a background in case management to shift to a planning/brokerage support role where the person living with disability is driving the arrangements. Conditions for this include the professional person's support for the philosophy that underpins Individualised Funding, and good orientation to the framework.

In considering the role of a support person to help planning and brokerage, it is important to note that people's personal competence is not necessarily static. For any of us, our capacity to make a decision can be affected by circumstances such as ill health, bereavement, fatigue, use of alcohol, drugs and medications, emotional feelings, and so on. This will therefore also be true for a person living with disability.

This means that there is some onus on the person in the planning and brokerage role being able to issue clear guidance (but not make the decisions), for example in respect of the person wanting to access products/activities that are illegal, or where the person's competence to make a decision is being affected by a particular circumstance.

It is important to remember that the availability of someone to assist with planning and brokerage is, in itself, an option and it should not be assumed that every person living with disability will need or want such assistance. A person may prefer instead to rely on her/his own capacity to identify and build a framework of support.

Support to Manage

Individualised Funding means that the person living with disability carries responsibility for purchasing and managing her or his own support services. This includes a range of legal and financial considerations that go with carrying accountability for the public funds and the staff involved.

In our communities, many self-employed people will use the services of an accountant, a lawyer or a business bureau, to assist them to meet their legal and financial obligations. This is also the case for people using Individualised Funding arrangements. The entity they use is described in a number of different ways. In the US, for example, it is referred to as a *fiscal intermediary, and* Nermey and Shumway summarise the role thus:

> "This organizational/intermediary function allows individuals with disabilities (or families) to serve as the employer of record (or this other intermediary, individual or organization can become the employer of record) for any staff hired to provide supports and allows this other organization or individual to manage all tax filings and payments to these staff. Fiscal intermediaries simply provide technical and fiscal supports without usurping the primacy of the individual with a disability, family and friends."

The last sentence is key, because it makes the all-important point that the person living with disability is still in charge. The Fiscal Intermediary provides a service that keeps the person safe in a legal and financial sense, without compromising the person's fundamental self-determination regarding the support arrangements.

Because the term Fiscal Intermediary suggests a role that is confined to money management, for the remainder of this paper I will use the term *host agency.*

Any organisation, entity or individual can feasibly become a host agency for a person living with disability, so long as the person freely chooses this while remaining in control of the decisions that affect her/him, that the tasks are performed as expected, and that there are no significant conflicts of interest.

Interestingly, in British Colombia, the host agency role has in some places been undertaken by an entity called a *microboard*.

According to the Vela Microboard Association's website,

> A Vela Microboard is formed when a small group (micro) of committed family and friends join together with a person with challenges to create a non-profit society (board). Together this small group of people address the person's planning and support needs in an empowering and customized fashion. A Vela Microboard comes out of the person centered planning philosophy and is therefore created for the sole support of one individual."
>
> *Vela Microboard Association*
> http://www.microboard.org/index.html

In their review of Individualised Funding in an area of South Wales, Stainton and Boyce (2002) reported that people using the scheme valued highly the role of the host agency. Interestingly, people particularly valued the fact that the host agency's staff were themselves people living with disability.

Polivka and Salmon (2001) found that between 75 and 80% of people in Individualised Funding programs across the US chose to go through a host agency.

7.0 Reported benefits

Stainton (2006) notes that the vast majority of the available literature shows a big increase in positive outcomes, including quality of life, satisfaction, and independence.

Poll et al (2005), in evaluating a pilot study in the UK, reported dramatic increases in satisfaction, cost savings, and community support.

Over ten years ago, Doty et al (1996) found a strong correlation between consumer choice and consumer satisfaction, and that was heightened when agencies encouraged consumers to hire their support staff directly. They found that the person's active involvement in the hiring and management of support staff, including whether they knew the people prior to employing them, all contributed to overall satisfaction with services.

Conroy et al (2002) spent three years looking at schemes across 42 US states, including a more detailed examination of 6 states in particular. They developed a hypothesis based on the impact of self-determination:

> "If people gain control, their lives will improve and costs will decrease."

The results were striking. In each of the states they looked at, they found evidence (through measures such as the degree of shift to person-centred planning, and the extent of decision control) that people did indeed have more control. They found significant improvements across 14 quality of life indicators (for example regarding client/family perceptions of choice-making, getting out and about, socialising with friends, and health), that life did indeed improve. Finally, although adequate financial information was limited to only 3 states that they looked at, they found that costs were favourable when compared to traditional arrangements.

Lord et al (2006), in their study of initiatives in Canada, concluded that Individualised Funding had a positive impact on quality of life, as reflected in areas such as making choices, achieving goals, participating in the community, and growing relationships.

Frogue (2003) cites evidence across a number of studies that satisfaction rates are high with this model, and without any negative effect in terms of costs. The USA's National Council on Disability (2004) found positive outcomes in respect of consumer satisfaction, quality of life, and perceived empowerment, and no downside in respect of any safety compromises.

Western Australia's Disability Service Commission (2003) reported the review of its Local Area Coordination (LAC) framework, which found that the framework (which has the ability to conduit funding directly to clients) achieved good results in terms of service coverage, cost, and consumer satisfaction.

Stainton and Boyce (2002), in a Welsh study, reported key benefits in terms of perceptions of independence, client control, perceived value, and cost efficiency.

Geron (2000) notes how the advent of the model has resulted in a new perspective on service quality, one that is driven by the person living with disability. Given that it is a person who is crafting the support arrangements, and employing and directing the staff, s/he is in the driving seat in terms of how quality is defined and measured. As such, the model serves as an important vehicle for acknowledging, and *heeding*, the voice of the consumer.

Taking this further, Polivka and Salmon argue that Individualised Funding, in addition to being exceptionally popular with its participants today, also supports the future:

> "By giving consumers the flexibility and independence to spend their money as they see fit, [Individualised Funding] encourages the evolution of long term care services that are responsive to consumer needs rather than to government regulations."
>
> *Polivka and Salmon (2001, page 20)*

They also argue that, through its focus on the consumer and her or his network of family and friends, the model can make a critical contribution to the capacity and sustainability of the informal systems of support in people's lives.

> "it is compatible with a broad commitment to the value of public policies that strengthen the family and support its capacity to care for [relatives with impairments]"
>
> *Polivka and Salmon (2001, page 41)*

Extrapolating from this, it suggests that Individualised Funding actually helps grow the extent and range of informal supports in someone's life.

The benefits are thus summarised by Glasby and Duffy:

> "…all the available evidence suggests that [Individualised Funding] leads to greater user satisfaction, to greater continuity of care, to fewer unmet needs, and to a more cost-effective use of scarce public resources"
>
> *Glasby and Duffy (2007)*

Finally in this section, it is worth noting that Individualised Funding offers portability. The person accessing Individualised Funding is likely to have an increased capacity to easily make changes in their arrangements, rather than being tied to broader arrangements that at times may have more to do with the needs of service agencies than the needs of the clients they're meant to serve.

However, is it all good news?

8.0 Challenges to the approach

No system is a panacea in and of itself. Any service system, in any field of human endeavour, can carry within it the potential for good things to happen, and the potential for bad things to happen.

In respect of Individualised Funding, it will therefore not be unusual to find that there are potential pitfalls, such as the following.

Exploitation of clients

A concern could be that with people charged with putting in place their own arrangements, they could lay themselves open to abuse. This could be on the basis of the assumption that it is easier to ensure safeguards for vulnerable people if they are either physically, or organisationally, congregated.

However, there are plenty of examples around, be it in the literature or in the stories that people tell about their experiences, which suggest that 'traditional' sector arrangements are not necessarily all that good at protecting vulnerable people from neglect and abuse.

Doty et al (1996) note that in the Massachusetts arrangements, there was a significant investment in growing the capacity of people living with disability to manage their own arrangements.

Phillips and Schneider (2004), in harvesting a wide range of practical wisdoms in their study of arrangements in Florida, found that the exploitation and neglect of clients was rare, and there was no reported evidence that people were more at risk than in previous more traditional arrangements.

A related concern has been the perceived incapacity of people living with disability, especially those with cognitive impairment, to manage their own arrangements. The above capacity-building argument, as per the Massachusetts example, still applies. In addition, methodologies such as Circles of Support and Microboards provide significant support for vulnerable people to make their own decisions.

Interestingly, Stainton and Boyce (2002), in their Welsh study, found that such concerns were largely held by professional staff with no direct experience of the framework of Individualised Funding. Those professional staff that did have familiarity with the framework tended to be more accepting of the person's capacity to manage their own arrangements.

Glasby and Duffy (2007) note that, far from being exploited, people living with disability, or their advocates, take advantage of the opportunity and demonstrate their capacity to make effective decisions because they have a strong vested interest.

It will cost more

The numbers of participation remain relatively small compared to the overall population of people living with disability, so it is hard to find compelling evidence that Individualised Funding costs more *or* less than traditional arrangements.

However, in each of the places where Individualised Funding has been made available, it is likely that there will be public fund administrators who have a keen interest in the financial effect. If there was a distinct trend for service costs to go up, one could reasonably have expected those administrators to signal this.

What evidence there is does suggest that costs do not increase significantly, and can often compare favourably with traditional alternatives (e.g. Conroy et al 2002, Frogue 2003, Stainton and Boyce 2002). Early evidence from the U.K. points to at least a 12% cost saving as a result of people being able to direct their own support (Duffy 2006).

Gathering data can be a challenge. It is not always straightforward to set up a control group to compare costs, because of the range of variables that can come into play. However, if a person was previously receiving services under a traditional funding mechanism, it ought to be relatively straightforward to translate that into dollar terms. This figure provides a baseline measure, and also can be used as an indicative working figure for the Individualised Funding, which can then be tested using whatever assessment tool the funder has chosen. Interestingly, if in this scenario the funding costs *did* increase, this would not necessarily mean that Individualised Funding is more expensive, but may in fact point to problems of assessment, be it the traditional assessment methodologies, or the one chosen for Individualised Funding. In other words, it may be poor implementation that is causing the problem, rather than the idea itself.

No take-up of the opportunity

Low take-up can be an issue. As with most things, if people don't have enough relevant information about something, they are less likely to actively support it.

It follows then that there has to be an appropriate investment in ensuring all key stakeholders – people living with disability, their families, support agencies, staff – have access to good information. Phillips and Schneider (2004) note that advocacy agencies can play an important role in getting information out to people living with disability so that they can make an informed choice about whether to move into Individualised Funding arrangements. In contrast, the same authors also note that agency resistance, and competing staff priorities, can potentially diminish take-up.

Government also has an important role to play in setting up the appropriate conditions for Individualised Funding arrangements to flourish. Indeed, Glasby and Duffy (2007) note that low take-up doesn't necessarily disprove the concept, but instead could reflect poor implementation. They also note that greater success often comes when a user-led information/advice agency is available to assist a person to decide whether the option is right for her/him.

Diminishment of professional safeguards

Laragy (2002) notes there could be concerns whereby the direct involvement of people in orchestrating their own support arrangements could mean the removal of those safeguards that exist by virtue of the involvement of professionals who, in addition to their own knowledge about risk issues, perhaps at times act as a counterbalance to the pressures placed on people by their own family and other people providing support.

Again, the presence of support systems like Circles and Microboards can help mitigate this. There is also no reason why an Individualised Funding framework cannot carry an appropriate suite of system safeguards without being invasive or diminishing the person's opportunity to make personal choices about services.

Exploitation of staff

Another stated concern is that a system of Individualised Funding can cause a reduction in salary and benefits for staff working in the industry. The assumption is that, by having a large number of individual people living with disability entering the market place as purchasers, it will create increased competition among service agencies, who may, among other things, consider reducing their prices to get a market edge. Such service price reductions are often associated with reduced staff salary and benefits, because staffing costs are the main influence on price in the disability support sector.

An associated concern is that staff benefits are at risk of diminishment where they are working for a small, or single-person, agency, perhaps without the infrastructure to provide conventional staff benefits.

The summary catch-cry for those cautious about a framework of Individualised Funding is that it results in 'staff on the cheap'.

However, a look at the examples of Individualised Funding frameworks elsewhere shows that this is not bound to happen.

The program in Massachusetts, as reported in Doty et al (1996), found that in fact support workers involved with Individualised Funding worked to a better hourly rate than the typical agency rate in other states. Part of the key to success was the very small administrative charge levied by the consumer-run entities that administered the program.

Doty et al go on to note the variations across US States in pay rates for both individual and agency-employed staff.

It cannot be concluded that a framework of Individualised Funding will inevitably lead to a diminishment of staff benefits, with at least one example showing that the reverse was the case.

Also, Lord and Hutchinson (2003) make the point that Governments have a key role to play in setting employment guidelines. As such, one can reasonably expect Government to establish regulatory safeguards that help ensure that, within a framework of Individualised Funding, the disability support workforce is treated fairly.

Interestingly, Lord et al (2006), in their study of four areas, noted that many families reported that staff remained for years. This suggests a low turnover, and the researchers also noted that clients reported high levels of satisfaction with their support staff, who also played a valued role in using significant time linking clients with opportunities in the wider community. As such, this suggests that a framework for Individualised Funding can bring greater job satisfaction to support staff, in terms of client appreciation, and role diversity.

Diminishment of agency sustainability

Another concern could be that service provider agencies might have their sustainability damaged by a shift to a framework of Individualised Funding, which arguably means there would be an overall loss of sector capacity and consumer choice.

It is certainly true that an informed person, buying personal support, will make choices between service agencies. These choices will be based on the main parameters of quality, price, and brand (familiarity and reliability). Assuming that there are framework safeguards that avoid a price war that gouges staff benefits, the main choice-making will be on the basis of service quality, reliability, and agency administration costs. It is therefore arguably a good thing if some service agencies subsequently have a sustainability problem, because they are not competing well in respect of quality or reliability or administration efficiency. This situation does not stop new entrants to the market either, who profess (and can subsequently demonstrate) a well-run, high quality, reliable service. As such, the arrangements do not diminish choice, they enhance and reinforce choice. In short, the arrangements provide incentives that encourage service agencies to be more responsive.

The framework can challenge service monopoly, and can also challenge the levels of administrative charges that agencies include in their service prices. The Massachusetts example shows the ascendancy of those agencies with low overheads, transferring those savings into direct client support from motivated, relatively well-paid staff.

Lord and Hutchinson (2003) note that Government can play a role overall in supporting the overall sustainability of the non-Government sector in this framework, by investing in infrastructure support and technical support. Western Australia is given as an example.

The Burden of Accountability

Even allowing for the availability of support to help the person navigate the legal and financial obligations, the fact remains that the responsibility may be a joy to some and a burden to others, more so the latter if the funder places heavy demands in terms of accountability reporting. The US System, driven by the features and imperatives of the Medicare and Medicaid systems, appears to place a heavy burden of bureaucracy on people in charge of their own funding, while the UK, for example through the efforts of the organisation In-Control (www.in-control.org.uk), appears to be nurturing a framework that emphasises minimal bureaucracy.

Bureaucrats who expect people to fail at organising their own support, can help this to become reality by imposing heavy bureaucratic demands.

Alternatively, the lighter the bureaucracy the more likely it is that people will succeed in managing their own arrangements.

Limited horizons

One problem is that it is dangerous to assume that once a person is in charge of funding, s/he will automatically make better purchasing decisions than the Government. People are more likely *not* to succeed if they do not have access to information and support to undertake the role as purchaser of their won services. In this way, people can be set up to fail.

More than this, there is the added consideration of the person's view of what is possible. If this is limited to the history of their personal experiences, then for many people living with disability and their families, it may be that they will buy services in a similar vein, in order to 'stick with what they know'. This means there is less likely to be a significant change in the quality of what is provided, which in turn could, in the eye of Government administrators, diminish the argument for people having control over their own funds.

It is no surprise that horizons can be limited in this way. People living with disability are more likely to be exposed to experiences of marginalisation, where the views and actions of others have 'trained' people living with disability to have lower expectations of what is possible in their lives.

To counter this requires a genuine commitment from Government and the community to embark on a patient and thoughtful journey with people living with disability and their families, to reclaim an aspirational sense of what is possible in their lives. This is not limited to direct work with the person, but extends to the Government and community leaders growing the community's capacity for inclusion – building access, public transportation, mainstream employment, a decent education, and so on – so that the view of what is possible begins to extend beyond personal care tasks, household support, therapy and meaningless diversionary activities, and more into a rich associational life within the wider community.

However the introduction of Individualised Funding should not be delayed for this to happen, because that would deny people the opportunity to 'learn through doing'. In other words the journey must *start* with the principle of self-determination, not end with it.

Individual and community

The emphasis of the model is on the individual, who is supported to make personal decisions and enter into individualised arrangements. This opportunity to tailor the support arrangements to the individual is important and attractive. However, we are individuals within communities and people rarely operate wholly in isolation. Support arrangements tend to be stronger and more sustainable when they are anchored within community networks and community relationships.

There may be a risk, therefore, that someone endowed with an Individualised Funding opportunity may only focus on the practice of the individual purchase, which could become quite isolating as the person spends time only with paid staff whom they have contracted to be there. In this way, the person may inadvertently disregard building broader relationships of goodwill in the community.

The danger of perceived panacea

A pivotal issue is the extent to which the system sets people up for failure. In other words, the notion of *Individualised Funding,* in and of itself, is no guarantee that people will get better supports and a better life. As such, the greatest risk is doing it badly (as per any of the above-mentioned challenges), or assuming that no other part of the overall system needs to be addressed.

Individualised Funding is only a partial solution if it just involves part of the disability funding available. For example, if the only Individualised Funding available is for personal support then there will still be barriers in respect of issues where the funding comes from elsewhere, issues such as support to access open employment, or assistance with mobility.

Also, any number of factors can conspire to trip Individualised Funding up. The capacity to buy one's own support services is but one element of a range of supports that can assist a person to live a decent life. A framework of Individualised Funding, delivered without appropriate safeguards, without an integrated framework, without an emphasis on capacity-building, and without a thoughtful understanding of exactly what the person wants to do with this life, will increase the likelihood of disappointment.

However, none of the above factors disprove the concept of Individualised Funding or its potential for adding significant value in the lives of people living with disability. Indeed, the UK's Commissioner for Social Care Inspection identified in their 2004 report a range of issues that were undermining the successful take up of the options, yet were able to recommend a range of practical measures in response.

9.0 Summing Up The Opportunity

The growth in various applications of Individualised Funding over the past twenty years, together with the positive feedback from people involved, suggests that it is here to stay and that increasingly it will become a standard option within disability support systems.

Also, the simple fact remains that you can only buy so much, and funding cannot replace other elements necessary for a good life, such as the freely given association of others, like friends and neighbours, and participation in community life. Individualised Funding will work best in this context.

Accordingly, Individualised Funding is increasingly a feature of advocacy agendas, for example the Disability Agenda authored by the Disability Rights Commission (DRC) in the United Kingdom and which was developed as a result of consultation with the disability community. The DRC called for individualised budgets throughout the UK, and this principle of Individualised Funding is a feature in three of their recently released policy papers, in respect of personal support, ending poverty, and tackling health inequalities (Disability Rights Commission 2007, x 3).

There is enough evidence of the benefits of Individualised Funding, and the safeguards that need to be attended to, for it to reasonably feature as a standard option right now for people within the disability community in every jurisdiction.

The elements that favour its success include:

- ❑ Early access to information about the options
- ❑ A tangible body of resources that are genuinely under the control of the person
- ❑ The availability of support to assist the person to set out a personal vision, to identify support needs, and to organise arrangements that the person wants
- ❑ The availability of support to assist the person control a range of management and compliance issues associated with being a budget holder, and an employer/director of staff
- ❑ A Government-endorsed framework of appropriate safeguards and evaluation
- ❑ Government commitment to regulating market conditions to avoid abuse and exploitation of one or more of the various stakeholders
- ❑ The availability of resources that support authentic person-centred planning
- ❑ A distinct and heartfelt emphasis, shared by all stakeholders, on individual/family/community capacity-building, so that there is a blend of paid and unpaid (freely given) supports in the person's life.

- A culture of relationship and integration
- Collaboration between funders, so that Individualised Funding supports a range of lifestyle issues
- A framework that is free from burdensome and invasive bureaucracy
- A default assumption that people living with disability and their families have the capacity to be successful in organising their own support

This is in no way intended to read like a ‘too-hard’ list, but rather as a highly achievable primer for putting in place new arrangements that give people living with disability and their families a greater degree of control over how they build support to access the same opportunities as other citizens.

As Duffy notes:

> “Self-directed support shifts the economic paradigm from one where the disabled person is simply seen as a recipient, to one where the disabled person is a full and active social and economic agent”
>
> *Duffy (2006)*

As I hope this paper has shown, there is now plenty of evidence in support of the concept of Individualised Funding.

More and more people, in more and more jurisdictions, are taking up the opportunity of Individualised Funding. For any Government not currently offering Individualised Funding as a routine option to the disability community, a ‘wait and see’ approach is no longer a credible reason for inaction.

If a Government is truly committed to values of self-determination, inclusion, and capacity-building, then the introduction of Individualised Funding is well overdue.

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Appendix C

Individualised Funding-General considerations on implementation

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Individualised Funding

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1.0 Summary

The availability of Individualised Funding is essential to the empowerment of the disability community. This paper continues an analysis commenced in Williams (2007). Using an approach derived from the McKinsey 7S approach (Waterman et al 1980) the paper sets out the key considerations underpinning the successful implementation of support arrangements where the person living with disability has control of the funding (here described as *Individualised Funding*). The analysis emphasises a habit of collaboration among a range of stakeholders, and with particular reference to the genuinely heartfelt values that need to be present.

2.0 Considerations for Implementation, Including General Policy Settings

The argument in Williams (2007) puts the view that the concept of Individualised Funding has demonstrated its worth and place as a standard option within a disability support system, and has identified the key elements for success.

The next examination must therefore be the considerations for its implementation, including policy and practice leadership. An effective organisational framework, must have regard for a range of practical issues, including the declaration of values and strategic intent, system and structure arrangements, competencies, staff, and cultural fit.

The following analysis uses as its framework the McKinsey 7S approach (Waterman et al 1980). Consultants at McKinsey developed this model to help administrators effect organisational change. It focuses on the alignment of seven key areas of organisational activity. These can also apply to a collection of organisations, such as those within a service system. Such alignment is essential if Individualised Funding is to take its place successfully in disability support arrangements.

The following analysis offers the sequential elements to which a coalition of stakeholders should commit, if our communities are to make a decent go of Individualised Funding. It also captures a number of the summary recommendations from the UK's Commission for Social Care Inspectorate (CSCI) report in 2004 on Direct Payments.

At the outset, I now make what I consider the *Fundamental Point* underpinning the successful implementation of Individualised Funding. It is this: successful implementation does not lie solely with Government. While government has a considerable role to play in sustaining a vision for change and overseeing the practical arrangements underpinning Individualised Funding (and this is reflected in the language used throughout this paper) it would be wrong to conclude the leadership belongs to Government alone.

Government policy makers and administrators cannot by themselves develop faithfully-built arrangements that deliver the benefits associated with Individualised Funding. Staff within every organisation, including Government, are subject to enormous pressures which compete for time and attention and thereby diminishing capacity for any specific initiative. To deliver the vision and policy of Individualised Funding takes *courage*. People at every level - Government officers, line managers, service staff, people living with disability calling for change - need support to maintain and exercise that courage.

So, the successful implementation of Individualised Funding requires a coalition of effort, where the voices and endeavours from a range of places - people living with disability, their families, their supporters, service providers, local community organisations, and of course Government staff – work together to create a collective momentum. This momentum includes collective leadership and collective courage, to create a framework for Individualised Funding that gives people the genuine means to build authentic lives of personal authority and social inclusion.

As such, the following analysis applies to all of the above stakeholders. We succeed or fail together.

2.1 Shared Values

Our society is shaped by individual values. Each person negotiates their stance in relation to the liberties and constraints they encounter. Within society, where people hold values in common they can support the status quo, engender change or resist change. The shared values become the basis for action. Behind this paper is the assumption that people living with disability do not experience the liberties others in society take for granted and the constraints they face exceed the constraints of others. There is a need for change. In this section, the key values motivating this movement are identified.

Based on evaluations cited in Williams (2007), a cornerstone value for Individualised Funding is the notion of *personal authority (*also linked to concepts such as *informed choice, self-determination, free will* and *independence).* It is absolutely critical that a wide range of agents - Government policy makers and leaders, service provider staff, and those of other organisations and groupings involved in the lives of people living with disability and their families - commit to this, and fully embrace it intellectually and emotionally. Such a commitment to personal authority infers acceptance of the obligation to support people exercising their discretion and independence. This ability to make choices for ourselves and to give voice to our views is the gateway to full and active citizenship. In other words, each agent (Government and others) welcomes the responsibility and accountability to ensure every person gets the resources and support they need to exercise personal authority and live active lives of citizenship. In the UK, the organisation *in Control* refers to this as 'independent living'.

This is a critical test for any organisation and its support of people with a disability. An agent unable to sign up to this value has no real interest in supporting people living with disability to live decent lives, indicating that independence of thought and action is less important than, say, passive compliance.

A second key value is *interdependence*. In other words, we recognise no person is an island, and that societies and communities have evolved, because of the extent to which every one of us depends on a range of different people for things to help us build our lifestyle. By association, this means communities need to be *inclusive* of all their members, including people who live with disability.

A third key value is *capacity-building.* This value recognises that throughout our lives, we continue to learn and grow. This is true for each of us as individuals, as families, and as communities. This demands that any successful framework for Individualised Funding must have the idea of capacity-building woven into every encounter.

Underpinning this movement is a vision for inclusion and participation that empowers each person within the disability community to exercise personal authority, participate as active citizens, and to grow. Each agent, including Government, needs to express these cornerstone values in the form of a *vision*. This vision and values must then shape public expenditure and public accountability. Similarly, service provider agencies and other relevant organisations, including those involved in advocacy – need to formally express these cornerstone values in ways that guide their work. Critical to success will be the extent to which the disability community is supported to participate in the ongoing crafting and shaping of this vision and the plans and actions which flow from it.

Referring back to the Fundamental Point, it is important the coalition commonly subscribes to, and embraces, these values at every level, and participates in the development of the vision so there is a shared ownership.

2.2 Strategy

While a clear value base is fundamental to any human enterprise, it is hard to achieve any change without charting a course. So, to give effect to the above shared values, Government, service providers and other relevant agencies need to state in detail what they will do. This is a critical act of formal and psychological commitment.

The strategy needs to clearly describe an intentional pathway to a set of tangible goals with explicit and coherent reference to the values and vision. This description must identify the key policy settings for success. When Governments consider the framework of Individualised Funding, they must address:

- The extent of collaboration between different funding bodies, to create a single, integrated fund
- How the amount of available funds is calculated for each person
- The range of purposes to which those funds may be applied

Again, referring back to the Fundamental Point, Government staff will be significantly aided in this task if they are joined in dialogue with a wide range of stakeholders and as part of a coalition of shared leadership.

In addition, service providers and other agencies will need to evolve their policy settings, for example:

- How their services will be customised to authentically respond to the individual aspirations of people using those services
- How they will build the right kind of relationship between agency staff and the people using the services
- How people using the services are routinely consulted on the organisation’s work and are part of the organisation’s governance arrangements

Note a strategy is about a clear statement of intent, a description of what is going to happen. It does not have to be pages upon pages of detail, with an attempt to plan for every possibility. Such detailed work is time-consuming and ultimately futile. A degree of uncertainty is inevitable, because the world does not stand still simply because someone wrote a plan.

A good strategy will have the critical support from the coalition of stakeholders, stay true to the values driving it, and contain sufficient flexibility to adapt to a changing environment.

2.3 Systems

To make the strategy come alive, the coalition of stakeholders next needs to identify the systems necessary for the safe and successful introduction of Individualised Funding.

Systems will include, for example, the mechanisms and tools for communicating with and informing people about this option, how eligibility is determined, how people's assessments of their support needs are verified, how the money is made available, how people living with disability and their families make contact with potential support providers, how outcomes are measured, and so on.

Given the extent of individualised funding arrangements elsewhere, the process of developing systems need not be overly onerous. Existing systems in other places can be accessed and adapted to suit the local circumstances (e.g. Waters 2007; in Control 2006). However, a key feature has to be simplicity. If the administration of Individualised Funding is burdensome, then it will reduce the likelihood of success for the people involved.

The coalition can identify system safeguards, such as effective regulatory and audit frameworks, to help ensure people, their support staff, and funds are safeguarded against exploitation. In designing safeguards, it is important the arrangements are proportional to the true risk. This is important because it is not unknown for various agents to develop and maintain cumbersome, top-heavy systems removing value.

In other words, Government agencies, service providers and other relevant entities involved in setting constraints, need to presume the majority of people will make sensible decisions about their funds and service choices. These people need to be resourced to seek out information and support when they need it. Where individual circumstances suggest a person needs additional support, the support must be informed first by the value of capacity-building – how the person and those who support them can grow their capacity, for example in terms of knowledge and confidence, to make quality choices. The removal of control and autonomy must be seen as antithetical to these core values and occur only in rare and generally temporary circumstances. By using this approach, every agency will avoid burdening the many with onerous 'safeguards' that are really only helpful to the very few. A critical component in this process is the generation of affirmative and appropriate accountability where people are enabled to accept responsibility for their choices. Again, the assumption should be most people recognise their decisions have consequences and are content to live with those consequences.

Key to all this is the easy flow of information. All agencies within the coalition will need to review and simplify their systems so people can easily access, understand, *and measure*, what the agency offers.

2.4 Structure

These systems, and the decision-making they support, need to take place within a formal framework, or *structure*. Structures are the formal organisational arrangements showing how accountabilities are managed. This is a key issue, particularly when organisations become larger.

For example, a Government department administering disability funding may have a formal structure based on divisions of activity. This is a relatively neat approach for being able to easily coalesce, quantify and account for a particular area of endeavour. However, it does not necessarily make it easy for staff within one division to move freely through, and collaborate with, other divisions.

Good funding mechanisms demand the capacity for people to think and act through a spectrum of organisational structures. Structures that support *networking* and fast movement will be an important boost to the implementation of Individualised Funding.

This does not necessarily mean there has to be wholesale reform in Government or agency administration before Individualised Funding can work. It simply means thought should be given to how existing structures can provide sufficient wiggle room so people can work quickly across different areas in support of a well-integrated funding solution.

In practice, this will mean Government departments will need to support activities across existing streams and promote conversations among various areas. Similarly, service providers should avoid developing ‘silo’ structures where communications go up and down through formal line management accountabilities. Such structures teach staff the only valued communications in the organisation are those going up and down the silo, and if the silo is long enough (and three line-managers is often long enough) then communications can be lost or diluted even within the silo.

An essential feature of Individualised Funding is that people should not need to shape their life by regular and routine contact with Government agencies and service providers. Instead, wherever contact with the various Government agencies and service providers is necessary, it should happen in a smooth and connected way, enabling a person to get on with their life without undue waiting or re-telling.

The notion of structure extends beyond Government to the range of agencies involved in disability support and their relationship with each other. Often a person will relate to a number of different agencies; it is vital these agencies collaborate in support of the goals the person has set for herself or himself.

It is not necessary to anchor key sector-wide structural mechanisms to support Individualised Funding within a Government structure. In the spirit of coalition as set out in the Fundamental Point, the structural arrangements could be anchored with another stakeholder or at various points within the coalition. For example, the UK-based organisation *in Control* provides support for several aspects of the Self-Directed Support framework in the UK.

It is essential that all structural arrangements should reflect the key values of self-determination, interdependency and capacity-building. As Individualised Funding comes to life, new organisations are likely to emerge, such as those supporting Circles initiatives (Russell 1995), Microboards (Vela Microboard Association 1997), and similar structures available to assist people to grow in their choice-making.

It is critically important Government fosters the emergence of ‘consumer-led’ organisations (where people living with disability and their family members are centrally involved in the governance arrangements). It is clear from people’s experiences (for example see Williams 2007) such entities are often valued highly by people living with disability and their families, because they comprise people on the same journey, and with similar experiences, with natural insight to the aspirations people have and the issues they encounter. Such organisations can have the capacity to support the person and their family with information, planning, brokerage, and management of support arrangements. Their presence is an important affirmation that people living with disability and their families are taking control and leadership of disability support arrangements.

The structural arrangements should include the formal involvement of people living with disability participating in the overall stewardship (governance) of the arrangements. Indeed this will be critical because running a framework of Individualised Funding is likely to be an ongoing journey, and there will be a variety of issues needing resolution along the way. Some of these issues will be practical in nature, some strategic in nature, and still others will be ethical in nature; all will have the capacity to either strengthen or weaken the framework. A coalition steering group comprising a range of skills and perspectives, including people living with disability and their family members, can be an effective mechanism to navigate through such issues.

Service provider agencies also have an important role to play in ensuring the voice of the disability community is heard and regarded. Service providers need to ensure they have structural arrangements at every level of the organisation enabling the disability community to influence the organisation’s decisions.

Finally, it is absolutely critical there are structures associated with advocacy. Each of us has a fundamental need to express our identity, our ideas and our wants. For some people within the disability community, this need may be frustrated, either because of aspects of the person’s circumstances or because of the person’s history of experience. Given the vulnerability experienced by many people living with disability, it is particularly important to ensure there are supplementary mechanisms, such as advocacy structures, to help ensure people’s voices are heard.

2.5 Skills (Competencies)

Competency refers to what people know and how they successfully apply it.

This means the coalition should be clear on the competencies a sector-wide framework for Individualised Funding, and the people working within it, needs to demonstrate.

This will include, for example, competencies associated with giving out information, and with assisting the person and family to establish an understanding of their needs and issues, including building a hopeful and aspiring vision of the future.

This in turn leads to the exercise of competencies associated with the development of an authentic person-centred plan, built on the person's vision for the good things in life, rather than being built on those existing service programs available in the local area.

The person at the centre and a passion to make it work

In supporting people living with disability, agencies often make one or more of three competency mistakes in planning with that person. The first mistake is the absence of planning. An agency may provide services to a person, but there is no emphasis on goals, growth or individuality. A shared statement of intentions is the first plank in a generative response.

The second mistake is planning but not genuinely involving the person at the centre of the plan. This defeats the purpose - it's somebody else's plan. Open and informed conversation must be the basis for the shared statement of intentions.

The third mistake is that agencies undertake too much planning with someone, and create a sense of orchestration in a person's life that exceeds what someone would typically do when thinking about the future. Finally, the shared statement of intentions based on open and informed conversation must be achievable and empowering.

The key is to ensure the person and their family own the plan and the planning process. This involves making use of the naturally occurring planning opportunities in people's lives. These tend not to be that formalised and tend to be based on the art of simply getting to know someone and their values and their dreams and goals, and how those dreams and goals are tested out with trusted friends and family, to gain feedback and encouragement and support.

So, for a framework of Individualised Funding to assist a person to access the decent things in life, it must include:

- a mechanism to identify with the person what they want,
- the way it will be talked through with people that the person trusts,
- the identification of how to make it a reality, the means of remembering so that people know what to do and stay focused.
- Above all, the planning process, and the people involved, must have the capacity to look beyond what is currently available, to exercise

> imagination, and to replace ‘why it won’t work’ thinking with ‘how it could work’ thinking.

Indeed, ignoring this last competency in person-centred planning will likely mean Individualised Funding will produce underwhelming results that “fail to really address people’s needs and potential to the degree they deserve” (Kendrick 2007).

Brokering relationships with and without money

The next set of competencies is associated with brokering arrangements in line with a person-centred plan. This will include developing sustainable informal networks that rely on natural community connections rather than paid relationships.

An implication throughout the framework is that hallmark competencies will be those associated with *relationships* rather than competencies associated with health and safety. Health and safety competencies often appear as hallmarks of traditional systems and are important, but should not be the predominant driver in the agency relationship with a person living with disability.

The prevailing competency for *any* paid staff person involved in Individualised Funding, be that staffer a politician, senior manager, policy worker, accountant, or personal support worker, is the capacity to engage the person living with disability and their family, so that person and their family feel they are respectfully placed at the centre of any decision-making affecting them.

Affirming personal capacity

Finally and most critically*,* while I have identified a range of competencies that feel important to the success of Individualised Funding, it nevertheless has to be assumed that people living with disability have the capacity to successfully administer their own support arrangements, either by themselves or through a nominated other. To *not* assume this will mean that formal and informal structures will collude to *exclude* people from administering their own arrangements.

And there is every reason to expect that people’s success will be enhanced by the simplicity of the system within which their personal authority can operate. In other words, people are more likely to exercise their capacity to manage their own arrangements if the system has been designed to be simple.
If the system is kept simple and straightforward, then the required competencies remain so as well. If the system is made to be complicated and sophisticated, then the same is demanded of people’s competencies, and this is quite unnecessary.

And unfortunately, as CSCI found in the UK (2004), people's opportunity (as opposed to capacity) to participate in the framework of Individualised Funding can be undermined by those around them, notably professional staff, who doubt the person's capacities and who are thereby reluctant to pass over the control. Therefore, it is of vital importance all key stakeholders *assume* all people have the competence/capacity to self-manage their support arrangements. There must be a corresponding focus supporting this to happen within a system that is easy to understand and move through (see in Control UK 2006).

2.6 Staff

Issues of staff recruitment and retention are prevalent in human services as for anywhere else. In traditional service systems, it is common for there to be difficulties recruiting and retaining staff.

Key to the success of a system of Individualised Funding will be the extent to which the system attracts and retains support staff who genuinely subscribe to the value base. For this to happen, the recruitment messages and associated material need to convey these values with passion and commitment. It follows that it will help enormously if people living with disability and their families are actively involved in the preparation and communication of those recruitment messages.

It is critical to understand the contribution staff make, and where the boundary lies between the contributions of people who are paid to be there (i.e. the staff), and those whose freely-given presence is motivated by things more enduring than money – common values, family ties, friendship, and so on.

It is therefore important any framework of Individualised Funding does not limit itself by assuming paid assistance is the solution to every issue identified. More funding for more paid assistance is not a panacea for many of the issues felt by people living with disability and their families. Financially wealthy people are not necessarily happy or fulfilled. This is not to say that funding is irrelevant. It is simply a matter of recognising that the role of paid staff only goes so far in the achievement of decent lives by people living with disability.

2.7 Style (Cultural fit)

The culture of an organisation/framework/system really comes down to the phrase, “the way we do things around here” and, by association, the way the organisation presents itself to the outside world. An organisation can declare feel-good values in its plans, but if the people in the organisation behave differently, then the true values, the true culture of the organisation, lie in the behaviour of the people rather than in the values written down in a plan.

It follows then, for a framework of Individualised Funding to succeed, the behaviour of those involved must consistently reflect the stated values. This is an ongoing exercise in vigilance and renewal, and places great expectations on those in leadership roles in all agencies within the coalition. This includes the paid staff involved in giving direct support, who must undertake leadership in their own practice and the way they build respectful relationships with the people they serve.

Therefore, the coalition (and the agencies within it) must ensure a common set of values are clearly stated for all to understand, and a commitment to work within them is pursued, exacted and measured within every document. This insistence must be clearly evident in any and all written materials, covering:

- the promotion of the framework
- the conditions by which people living with disability and their families are able to participate in the arrangements for Individualised Funding
- the parameters for what can be purchased within Individualised Funding
- the role and practice of planning and brokerage support
- the role and practice of financial /legal support
- the role and practice of support providers
- the role and practice of Government

3.0 Summing Up Implementation

Building a new set of arrangements, such as a framework for Individualised Funding, involves a number of considerations, including how to build a pathway from existing service systems.

There is a range of policy and practice questions to work through and plenty of opportunities for the people involved to get it wrong, albeit with the best of intentions. Hopefully, this paper shows the 7S analysis is a useful methodology to assist leaders to attend to the cornerstone issues. Chief among these must be the value base, and the existence of a coalition of stakeholders, to help maintain collective and individual courage in line with that value base. If the value base is clear, coherent and trusting of the disability community, then a robust and remarkably straightforward framework can be built. A thoughtful, well-organised approach, including the active involvement of, and leadership by, people living with disability and their families, will help ensure that the resulting framework has the capacity to add value in people's lives.

To echo a comment made at the outset, we succeed or fail together.

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