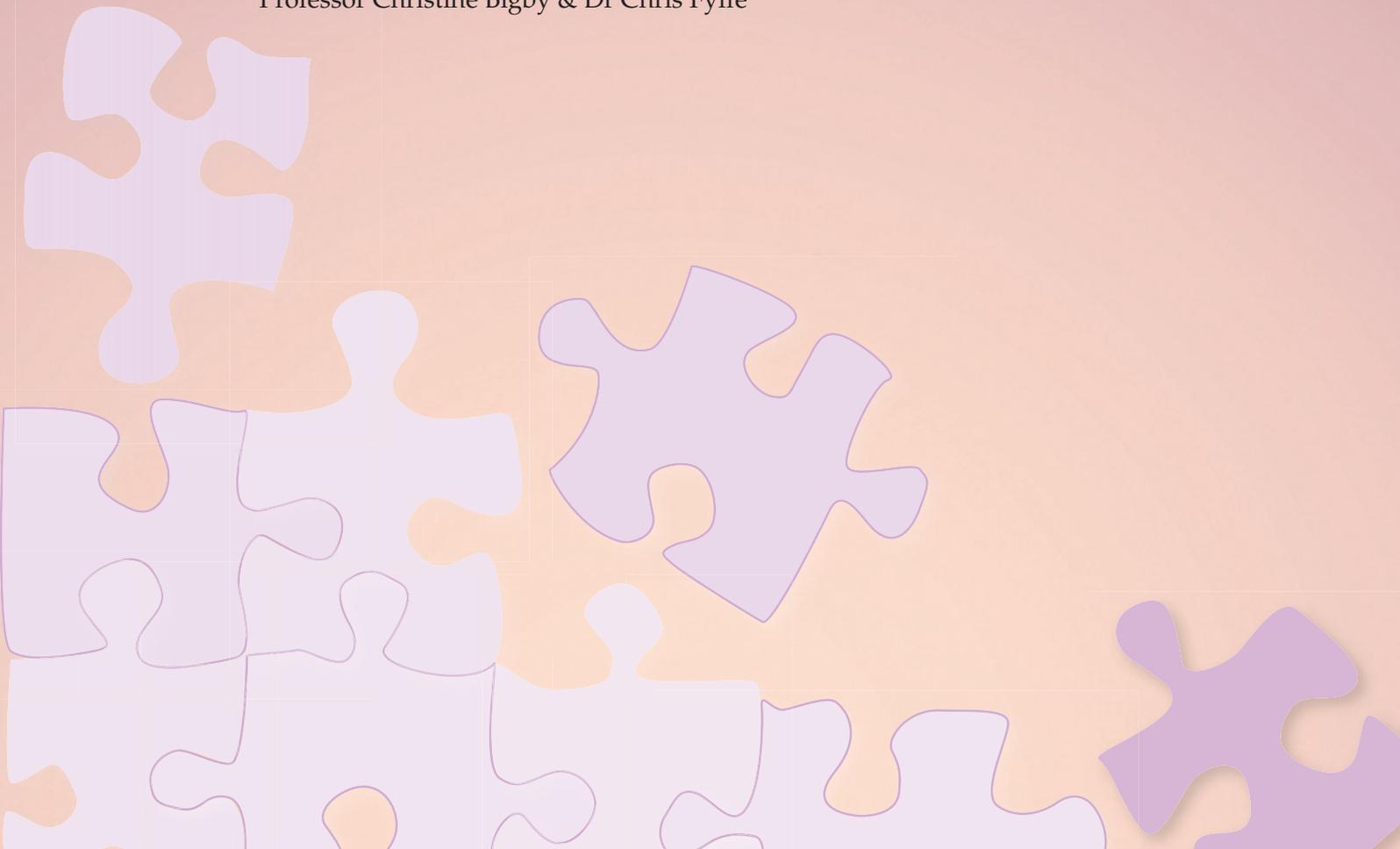


# **ACHIEVING THEIR OWN LIVES: THE IMPLEMENTATION OF INDIVIDUALISED FUNDING FOR PEOPLE WITH INTELLECTUAL DISABILITY**

**Proceedings of the  
Third Annual Roundtable on Intellectual Disability Policy**

**Held on Friday 24 October, 2008**

Edited by  
Professor Christine Bigby & Dr Chris Fyffe



ISBN 978 192 1377 600

Published by School of Social Work and Social Policy  
LaTrobe University  
Bundoora Vic. 3086  
Australia

Created by Allardice Group  
Blackburn Vic. 3130

Bigby, C., & Fyffe, C (2009).  
*Achieving their own lives: the implementation of individualised funding for people with intellectual disability*  
*Proceedings of the Third Annual Roundtable On Intellectual Disability Policy.*  
Bundoora: LaTrobe University.

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# AN OVERVIEW OF ISSUES IN THE IMPLEMENTATION OF INDIVIDUALISED FUNDING

*Professor Christine Bigby & Dr Chris Fyffe*

The Roundtable on Intellectual Disability Policy is an annual event convened by the School of Social Work and Social Policy at La Trobe University in collaboration with key stakeholders in disability policy, practice and program delivery. The Roundtable seeks;

*To provide a space for fearless debate, among interested groups, about policy within both the disability and the broader human service sectors for people with intellectual disabilities, with the intention of naming issues, clarifying concepts and ideas, exploring challenges, articulating solutions and informing practice.*

The theme of the 2008 Roundtable held in October 2008 was the implementation of individualised funding. This was in recognition that individualised funding (IF) is a key mechanism being increasingly used both in Australian and internationally to make service delivery systems more responsive to the control, choices and identified needs of each individual with a disability. However, the change to IF has been primarily driven by people with physical disabilities, about whom the bulk of research and commentary has been focussed. Little attention has been paid to the specific issues that arise in implementation of IF for people either with intellectual disability or to ensure that all members of this diverse population reap its benefits. As Laragy's (2009) paper highlighted, in Australia, very few people with intellectual disability have been included in trials of more sharply focussed consumer directed models of IF.

As in past years commissioned papers, circulated prior to the Roundtable, provided the catalyst for discussion. Three overarching questions were posed:

- What does individualised funding set out to achieve?
- What issues arise in implementing individualised funding arrangements for people with intellectual disability?
- What mid level policies/responses are necessary to maximise the potential benefits of individualised funding for all people with intellectual disabilities?

Collectively these papers contribute to identifying and understanding the critical issues that must be addressed in policy implementation to reflect the diversity of people with disabilities, and if people with intellectual disability are to gain similar outcomes to those already identified for people with physical disabilities. This introduction synthesises the key issues raised by the papers, and the varied perspectives RT participants contributed to the small group and plenary discussion. In bringing together these views, the purpose is not solely to critique existing policies but to add to knowledge that might inform policy.

## **The Nature Purpose of Individualised Funding - Choice and Control**

Tim Stainton's paper provided a review of international approaches to IF, proposing both a definition and the key elements of IF models (2009). Whilst recognising the tremendous variation in the design of IF models he defines it as:

*Funding allocated directly to an individual or in the case of a child their parents or legal guardian, to provide the support necessary to meet disability related needs and to assist individuals to become contributing citizens. IF has two fundamental characteristics: The amount of funding is determined by direct reference to the individual and/or family's specific needs, and aspirations; the individual and/or their family determine how funds are used to meet those needs eligible for funding (Stainton, 2009).*

He points out however that few jurisdictions have implemented both aspects, and more commonly control over funds continues to rest with service delivery organisations. Participants saw IF as part of a major cultural change in disability services, in which both governments and service providers hand over significant power to people with disabilities their families and allies which leads to the provision of more relevant and individualised support. Its purpose is 'to see individuals have their own life', rather than being slotted into existing programs and predetermined types of support and what might be perceived by others as a good life. Thus IF aims to give more power to people with disabilities to determine the course of their life, take the risks they choose, shape and control the type of support they need to do this. Allied is the sense that IF is a means to further the independence and social inclusion of people with disabilities. IF is seen to hold the promise of funding based on an individual's needs which will enable the purchase of flexible support that can be responsive as their life unfolds. IF is perceived not only as a funding mechanism but also part of the broader emancipatory movement of people with disabilities, aimed to shift them from dependence

on programs and services to citizens and subjects of their own lives.

IF models are designed to focus on the strengths and talents of people with disabilities rather than dwell on their deficits. They are inherently different from systems driven by crisis in which a person's weakness's and the fragility of their situation has to be emphasised to gain access to services rather than there being a planned response to need. However, some participants drew attention to the implementation of IF in WA and Queensland where families have to repeatedly plead their case and talk up their deficits to gain access to funding. This discussion illustrated the potential for funding models such as IF to be undermined by the broader context in which they operate. In Australia where there is no legally defined entitlement to service, and demand for funding exceeds supply, prioritisation of need is the initial step in gaining access to funding and IF mechanisms. As a result service users and their families may have to repeatedly expose personal deficits, as successful advocacy to gain funds is invariably based on deficits rather than strengths. This initial disempowering step to access funds may undermine the strength based approach to their use once allocated, which lies at the heart of IF.

### **Multiple Meanings of Individualised Funding**

The papers highlighted the many different variants of IF found both in Australia and internationally, and the various ways in which consumers gain choice and control over the use of funds. Although some commentators suggest IF suits particular groups of people with disabilities, such as those who are more articulate, have strong support networks, are willing and able to micro manage their funding and directly employ personal assistants, it was asserted that IF models can potentially encompass all people with disabilities. No one need be left out if a breadth of options are built into the model. This is particularly well illustrated in the Swedish system where choice exists in how individually allocated needs based funding is controlled and managed; directly by the individual; via small collective cooperatives or; by a larger more centralised service delivery organisation such as the municipality. Laragy (2009) suggests that a high proportion of Swedes choose to hand control of their individually allocated funds to the municipality, and therefore continue to receive a more traditional form of services. The Swedish system clearly demonstrates that IF models must extend beyond the simple option of 'hands on' control of expenditure. Drawing attention to the diversity necessary within IF models helps to

illustrate the potential roles that service delivery organisations will continue to play as service delivery systems change. For example, entering into a contract with an individual to supply a defined type of support at the time the consumer determines; contracting to manage allocated funding, planning and delivery of support to an individual which may include some one to one support but also participation in group based programs offered by the organisation; making a collective agreement with a small number of consumers to design and deliver individualised and group based support that draws on their pooled individual funding allocations.

### **Does Individualised Mean 'On Your Own'**

The meaning of individualised, particularly in the context of day programs or meaningful activities, was a key issue raised in the papers by Wilson and Campain (2009) and Craig and Cocks, (2009), which led to considerable discussion. Craig and Cocks gave a powerful description of the reforms at Gawith Villa (now Inclusion Melbourne), which had included unbundling block funding and a shift to individualised allocation of funds to each service user. (It is worth noting however that some day programs have been implementing such individualised programs in the community for some years. The distinctive element of an IF approach is the greater accountability that is achieved to each individual for their notional allocation of funds and the greater control they can then exercise over a known amount of funding). Such reforms meant that most service users had been enabled to participate in activities, that reflected their interests, in the community with other community members, rather than with others with intellectual disability. It was asserted these outcomes reflected service user choice, which had been tested through experimentation and exposure to different options. Once individual community activities had been experienced no one chose to return either to a Day Centre or to participate in groups of people with intellectual disability. The inability to offer these options to participants with more severe disabilities was seen by this service not so much as a failure of IF but illustrative of insufficient funding.

In contrast, participants in the Scope program described by Wilson and Campain, did participate with others with similar disabilities in group based programs, and it was argued they too had chosen to do so. The fundamental difference however in the new Scope program to what had existed under previous funding models was that participants were able to choose with whom they shared activities, based on preference and personal characteristics, rather than simply being allocated

to a group with others on the basis of attending the same day program or having similar needs. Another important factor to bear in mind is that it may not be the outcome or nature of activity that is important, but the process used to select it – is the activity a result of choice exercised by the person themselves or a service system decision based on organisational needs. The most pressing question that reoccurred throughout the discussion, was ‘how to demonstrate participants are more likely to have made an informed choice for themselves, based on knowledge and experience of all potential options and less likely to have had a choice imposed based on limited options or what others prefer they do’. An equally important question is ‘how and to what extent to acknowledge the restraint on choices imposed by availability of resources’. Clearly, IF alone will not solve this issue.

The discussions emphasised that individualised does not necessarily mean on your own, and it should not be assumed that person centred planning (PCP) or IF will mean that people with intellectual disabilities will not chose to spend time together, or will always prefer to be involved in activities with other community members. An identified concern was the potential for people with intellectual disability to become very socially isolated if individualised support is interpreted as one to one support from a paid worker. This is likely to happen if there is inadequate micro level planning for the use of paid support, and if rather than the support worker being a catalyst for the person with intellectual disability to participate in activities or build new friends and acquaintances, they themselves become a direct substitute for friends or meaningful activities. This led on to the question of whether all choices are acceptable within an IF system, discussed in a later section.

### **Individualised Funding is Only One Part of the System and Required Change**

The discussion identified the dangers in thinking that IF could solve all the difficulties experienced by people with disabilities. Such thinking might detract attention from the changes required elsewhere. It was clearly acknowledged that IF should be regarded as just one part of the disability service system and both its success and the broader social change required for people with disabilities to gain control over their own lives were reliant on other initiatives in other parts of the service system and the wider social context. IF as a funding mechanism, can’t for example, solve, shortfalls in funding for disability support, remove the systematic obstacles to social inclusion or access to mainstream facilities, health or community services, discriminatory or prejudiced community attitudes towards people

with disabilities, or poor staff or organisational practices. In fact it was seen that many of these factors served to undermine the potential for IF to deliver more choice and control for people with disabilities. Ilan Vizel’s paper, based on his Doctoral work on housing and choice, examined some of these broader contextual forces, such as lack of housing affordability and discrimination in the rental market, all of which undermine the potential of IF to increase consumer choice. There was also considerable discussion of the situation where small packages of funding were allocated without reference to greater and often unmet needs for accommodation or vocation support of the person. If IF is to deliver the potential it holds then its implementation must be paralleled by adequate funding levels that meet identified needs, and initiatives in other part of the social system. For example, people are unlikely to choose to participate in community based activities, if they experience negative attitudes from other participants or community members. Conversely, the success of IF for individuals will demonstrate possibilities for people with intellectual disabilities, which over time may well contribute to changing community attitudes about inclusion.

### **Gaining Access to the Mainstream**

In order to strengthen the capacity of IF models, strategies must be put in place to promote and support access for people with disabilities to the same quality of health, education and community services available to the general. In devising ways of doing this it is important to recognise the commonality between people with intellectual disability and other disadvantaged groups who find it difficult to access public housing and health services, and join with such groups in broad campaigns to improve universal access rather than competing with them for limited resources or specialist programs. However, it was recognised there are many strategies that can be adopted in gaining access to mainstream services for people with disabilities. In addition to more broadly based action, it was suggested that seizing the initiative by resourcing the mainstream to adjust and accommodate to the specific needs of people with intellectual disabilities is a way of modelling possibilities for inclusion, which may then, in the long run, be absorbed into mainstream practices and reduce the need for specialist initiatives, such as the nature of community development initiatives.

### **Implementing Individualised Funding – Taking Account of Diversity**

Much of the discussion focussed on the elements necessary to ensure IF is responsive to the particular needs of people with intellectual

disability. Rather than thinking about designing models for different sub-groups discussion recognised that if funding is to be matched to needs, IF processes must also take account of different needs. Different processes will be needed for different people which means, they must be designed and sufficiently flexible to take account of the diversity of people with disabilities and their social situations. The discussion can be summarised as the need to take account of:

- Differences in experiences, capacity to express choice, make decisions
- Differences in strength, composition and potential of informal social networks
- Differences in complexity of needs
- Differences in needs over time
- Differences in need for external case management, coordination or monitoring and review
- Differences in place.

### **Taking Account of Differences in Experiences, Capacity to Express Choice and Make Decisions**

Taking account of differences in experiences, capacity to express choice and make decisions was a core issue taken up in the papers by Ramcharan (2009) and Stainton (2009). Suggested was the importance of recognising that the very nature of intellectual disability means that people require support to make choice and decisions, but also that decisions vary in complexity and importance as well the frequency with which they have to be made. Different types of support will be required for different types of decisions. Highlighted too, was the often limited life experiences of people with intellectual disability which means they may have had little exposure to the diversity of possibilities for activities and lifestyle. These views, from the perspective of professionals and academics were also reflected in the perspective of the self advocates present. Reinforce surmised that many people with intellectual disability would need support to express their views, make choices and decisions.

A key challenges 'how to devise mechanisms that will support the maximum involvement of people with intellectual disability in exercising choice and decision making, which are sophisticated enough to recognise the diversity and differences in the nature, importance and complexity of decisions or choices to be exercised about a person's life and identify the different types of support each may or may not require to make different types of choice'.

In Victoria taking action for Guardianship and

substitute decision making power is the only formal way to deal with conflict or dissatisfaction about the decisions made by a person with intellectual disability, or by their family or a service provider on their behalf. The role of families in the lives of people with disabilities is recognised in disability legislation. As a result families or service providers seldom invoke action to seek the formal substitute decision making power of the Guardianship legislation for either day to day or more significant decisions. This due firstly to the reluctance to bring such action, and the associated dangers of escalating conflict between organisations and families, and secondly due to its restrictive nature which, by appointing a substitute decision maker, strips away the rights of the person with intellectual disability to be involved in decision making. As a result most decision making about the lives of people with intellectual disability, many of whom would be regarded as without the 'capacity' to make decisions, remains in the informal realm. Whilst service providers talked about respecting the role of families in decision making for people with intellectual disabilities, some gave examples where they were uncomfortable with decisions made by family members on behalf of adults (and it is quite likely that some families are uncomfortable with decisions made by service providers). Service providers did not however see it as their role to question such decisions and felt constrained in exerting undue influence or in taking formal action to challenge decisions. They pointed to the absence of processes to support informal decision making in the Victorian system, which would ensure the views or preferences of the person with intellectual disability, their family members and staff who knew them well were all taken into account. Ramcharan's paper suggested that concepts such as distributed or supported decision making are not found in Victorian policy, and the substitute decision making processes in the Guardianship legislation are inappropriate for use in the many types of day to day choices IF opens up for people.

Attention was drawn to the United Nations Convention on the Rights of People with Disabilities (2007), which refers to distributed or supported decision making, and the way this has been developed in UK and Canadian IF models. Both have developed guidelines and procedures whereby people with intellectual disabilities can share decision making with others that reflect the nature of their relationship with others involved, with different type of arrangements being put in place for different types of decision (see for example British Columbia's Representation Agreement Act 1996 discussed in Stainton, 2007, 2009 or Cramp & Duffy, 2006). In Control the

organisation in the forefront of IF development for people with intellectual disability in the UK suggest that planning processes must consider decision making of all kinds and set out who is to be involved in supporting a person with intellectual disability to make the range of decisions in their lives. They suggest the following principles to guide such thinking (Cramp & Duffy, 2006):

- The assumption that an individual has the ability to make decisions.
- Restrictions should only be placed on choice when a person doesn't understand the options, and their choice places them or others at risk
- If possible an individual should select who supports them in choice making.
- Different people are used for different types of issues.
- A good adviser or agent is someone with a good knowledge of the person, available options, is available when necessary, has no conflicting interests and is available for the long term.
- The individual always has the right to be involved and consulted even if someone else makes the decision.
- If an adviser or agent acts on behalf of a person the choice is made on the basis of "standing in the shoes of the person" the choice they themselves would make if they were able.
- Plans for who makes which types of decisions should be reviewed and updated.

Ramcharan's paper describes various mechanisms, such as micro boards, circles of support and support brokers that have been used in IF models in other jurisdictions to maximise the choice and control by people with intellectual disabilities. He argued decision making should involve those who love and care for the person, with safeguards to ensure the person's own involvement. He suggests however the overriding challenge is to nurture and build such a network for each individual.

The notion of an independent support broker whose sole role is to work alongside the person with an intellectual disability and ensure their perspective is taken into account as well as those of family and provider organisations was generally seen as critical for people with more severe intellectual impairment. Explicit supported decision making frameworks that make processes transparent, and decisions open to scrutiny were seen as essential to tailor IF to the needs of people with intellectual disability.

Whilst the potential for tensions to arise between the needs of family members, service providers and the person with intellectual disability dominated discussions, the situation of people, without strong family or other informal networks was also highlighted. Unless strategies ensure the availability of independent support brokers to represent their views, decisions for people in this group may be left with service provider organisations. Their situation also suggested that a key strategy of IF implementation should be to foster the development of circles of support for those without strong informal networks. This is critical if all groups are to benefit from IF, particularly as research from the US is beginning to suggest that IF favours people with stronger networks from more privileged social economic background (Neely-Barnes et al., 2008).

### **Taking Account of the Need for Flexibility, Iterative Planning and Case Management**

Wilson and Campian's paper written from their research with a day program for young adults at Scope, highlighted the creative patchwork of support that can be devised for each individual to reflect their choices. They also point however, to its finely balanced and fragile nature, that is vulnerable to unexpected personal, staff or situational change, such as illness of the person or support staff. Who, they ask is responsible for coordinating support and trouble shooting when things go wrong. From the perspective of a day program provider and just one of several service providers in the life of a person with high support needs, both Wilson and Campian (2009) and Craig and Cocks (2009), ask which service takes responsibility for planning and coordination and which if any is funded to do so in the proposed Victorian IF system. Discussions sparked by these papers suggested that people with intellectual disability, particularly those with little family support are more likely than many other groups of people with disabilities to need support from case managers for example, to coordinate support from different sources and trouble shoot when things go wrong or situations change. Service providers were concerned that the importance of this function may be undervalued in the planning process and allocation of resources. In the absence of factoring case management into funding packages, such functions may fall to provider organisations without reimbursement which means they may not be done as thoroughly as necessary or may remain undone.

Unreliable support arrangements will predispose people to 'choosing' more traditional structured arrangements. Coordination between different

providers involved in delivering support to an individual was a critical concern of service providers. Issues were raised about existing practices where a fragmented rather than holistic approach to support for an individual may be taken by each organisation. Rigid boundaries were described between organisations funded to provide different types of support to one person, that can perpetuate people living disjointed lives, if there are insufficient resources to permeate boundaries and achieve good coordination.

A third element of the discussion touched on earlier was the need for strategies to ensure that people with intellectual disabilities have exposure to a sufficiently different range of options and experiences for their choices to be meaningful. This suggests that time limited and episodic planning may not be the best strategy, but rather planning should be an iterative process that is spread over a long period, allowing new experiences and preferences to be continually taken into account in support plans. This discussion also showed the very many different types of plans that may be applicable in the course of service use, and the importance of differentiating the purpose of different plans. For example, is a plan at the micro level and a guide to the type of support that must be provided to a person in particular aspects of their day to day life, such as when they are at home, or at work, or is it an overarching and more broadly focussed set of goals about the future course their life might take. Whilst both are needed they are very different types of plan. In a related discussion attention was drawn to the difference between the 'original' type of PCP conceived by commentators such as John O'Brien, which stood outside the formal service system driven by a circle of supporters and the reality that state-wide IF systems rely on more formal planning processes closely aligned to the allocation of funding for formal support. This is evident in the research from the UK about PCP, and draws attention that only a minority of people have strong enough circles of informal support that are able to take carriage of PCP which can then be dovetailed with more formal processes. It suggests the importance of taking account of both groups, those with strong networks to support the type of PCP originally envisaged and those who will be reliant solely on more formalised forms of planning. At the very least these discussion suggested the need for much more clarity when plans and planning processes are referred to, and the need for policy guidance to delineate the type of plans being referred to.

Laragy's paper (2009) drew attention to the disdain the Swedish system appears to have for planning (though it seems this is to broader more generalised life plans, and it must be remembered that

Sweden has a backdrop of entitlement to support, which could render wider planning less relevant). This raised questions about its significance as a separate process in IF models and the investment made in it in the current Victorian system. Allied to this is the significant body of research that suggests though individualised planning at both the individual service and whole of life levels has long been at the basis of intellectual disability systems. Despite this the limited research on implementation suggests planning policies have not been well implemented, and have rarely achieved the quality set out in planning guides, attained the coverage of the population expected, or been fully implemented or reviewed (Roberston & Emerson, 2007; Bigby, 2007).

Whilst the advantages of separating planning functions from purchase of services, was recognised, the situation of people who have long term relationships with a provider challenges this to work in practice, and suggest it is critical that external planners recognise those relationships and involve existing providers as well as others who have known the person well over a long period. A further related issue was the need for flexibility in planning processes and funding allocations, to enable timely responses to changed support needs, some of which such as life stage transitions can be predicted and planned for in the setting of review dates for example, whilst others such as health or other crisis will occur serendipitously. That many people with more severe intellectual disability are likely to be life long service users underscores the importance of a funding allocation system that is responsive to both planned reviews and unplanned change. The need to build into funding packages and arrangements with support providers provision for emergencies, highlighted by Craig and Cocks was also endorsed during discussion.

### **Taking Account of Differences in Complexity of Needs and Place**

Ilan Vazel's paper identified the potential exclusion of people with high support needs from IF and argues that allocative mechanisms should be designed to positively discriminate in favour of this group. Craig and Cocks demonstrated the very real disadvantages that can result for people with high or complex support needs when funding to organisations is disaggregated and cross subsidisation from low to high needs clients is removed. It clearly illustrates that at existing funding levels people with high support needs (many of whom are unsafe without staff presence) remain locked into group based programs segregated programs, reliant on sharing 'individual' resources in order to obtain the level of staff support they require across the day.

The experience of Gawith Villa showed that current funding levels for people with high support needs are insufficient to provide the type of individual options available to other clients with lower support needs. The primary reason for this is that people with high support needs may have time intensive personal, communication and/ or behavioural support requirements and require, therefore, staff to be available at all times. Funding levels appear to assume some time in people's days can be left unfunded, which is not the case for this group. In the Gawith Villa model sharing support with a small group of others in a similar situation was the only way sufficient staff support could be purchased within existing funding parameters.

The choices and social inclusion of people with high support needs who have to share resources to gain support in their accommodation or with day time activities are often very precariously balanced. If one person leaves a group arrangement, the situation of others will be under threat due to insufficient funds to maintain the arrangements unless a replacement is found. In turn this may leave a person powerless to exercise any real choice about who the replacement is. Though this phenomena is associated with funding limitations and group based day or accommodation support that IF is hoping to re-shape, it was also suggested to occur in IF models. Vizel's paper (2009) for instance drew attention to a trend towards construction of accommodation settings larger than normal dwellings, as one response by the sector to the need (driven by funding levels) for people with high support need to share support. This may foreshadow a return to larger scale congregated setting for people with high support needs, which will inevitably obstruct community inclusion and individual choice. The trend for people with high support needs to be excluded from the potential benefits of IF system appeared to some RT participants to echo their exclusion from more innovative housing and support options identified at the 2007 RT (Bigby & Fyffe, 2008).

The complexity involved in assessing the support needs of a person with more severe disabilities was referred to, with the suggestion that if the system can get it right for this group, this is an indication of its capacity for people with less complex needs. The thrust towards purchasing specialist assessment for people with complex needs emanating from the Office of the Senior Practitioner was identified as a tension in a system where funding is scarce and expenditure has to be prioritised by an individual.

The argument in Vizel's paper for the importance of place based funding to build service infrastructure

and counter existing regional inequities in supply of services and skilled labour was supported by RT participants. Differences in the availability of service infrastructure and community resources was seen by participants as a central issue both between rural, regional and city locations, and between different urban areas. Both individualised and targeted place based funding approaches, for things like health, education, leisure or housing services needs to occur simultaneously, rather than being an either or situation. Place based funding was also seen as fundamental to building organisational capacity in an IF system which is discussed in a later section.

### **Knowledge and Involvement of people with Intellectual Disability**

Paul Ramcharan's paper (2009) pointed out the importance of involving the collective voice of people with intellectual disability in shaping policy implementation as one way of ensuring programs reflect the particular needs of this group. Though most participants acknowledged the substantial promise offered by IF, it was clear that unlike jurisdictions overseas, in Victoria developments had been largely led by government, rather than consumer groups. There was a strong sense that the leadership should be rebalanced with people with disabilities taking a much stronger role in developing IF models. The consensus was that people with intellectual disability, more so than any other disability group, had not been involved in consultations and design of the evolving Victorian system of IF. For example, the consumer advisory group to the DHS Assistant Director responsible for developing IF does not include or seek advice from anyone with an intellectual disability. Their involvement was seen as particularly critical given the number and diversity among people with intellectual disability and the particular issues that stem from intellectual impairment that require mechanisms for supported decision making and to safeguard decisions represent their views rather than the needs of others involved in their life. In the Canadian situation described in Stainton's paper, the composition of advisory/ governance bodies mandates the involvement of a specified proportion of people with intellectual disability (Stainton, 2009). If people with an intellectual disability are included in various ways at the State-wide level, a trickle down effect is more likely to occur at regional and organisational levels. As with other policy areas the point was made that if people with intellectual disability are to be involved, they must be well supported to participate. It is also important to ensure that quality information in plain English is accessible to self advocacy groups, people

with intellectual disabilities and their families. Reinforce stated that at least this state wide self advocacy group had little knowledge of IF. It was also suggested that a program such as the US Partners in Policy Making, specifically designed to increase the participation of people with intellectual disability could be piloted in Victoria, using IF as an exemplar policy area (<http://www.partnersinpolycymaking.com/>)

At the operational level, it was acknowledged that support and information about management of funds, employment of staff and other elements of the system need to be easily accessible, and an online support system, such as that offered by In Control in the UK was seen as one model for providing this (<http://www.in-control.org.uk>)

### **Balancing System Accountability, Individual Protection and Choice**

The tensions between different goals of IF came clearly to the fore in the discussions, and were captured by the comment, "Why do you want to make it so complicated – just give people the money." Participants were divided about the degree of control by government and accountability to both government and the individual that an IF system requires. For example, some thought control should be exerted over how allocated funds are expended. Ensuring support is only purchased from organisations or individuals registered under the Disability Act, and thus bound by the Disability Standards, would give more control over quality of what is purchased. In the absence of such provisions individuals are open to exploitation and more variable quality of support which might not be underpinned by legislative principles. Other participants were concerned that such rigid controls over expenditure would create too many inflexible and bureaucratic obstacles. Related was discussion about the parameters of individual choice, and whether it should be restricted to the parameters of the current policy, which for example recognises that large scale congregate care is in conflict with the legislative principles, or simply left without boundaries and determined by individual preference as long as these could be demonstrated as informed. Also considered was the degree to which planners or providers should intervene in situations where they felt a decision was poor, and if they did not, who would be left to bear the negative outcomes (this point goes back to issues about supported decision making and the use of substitute decision making). The complex application of concepts such as dignity of risk and informed choice are clearly central to such issues. Participants were very aware these do not lend themselves to procedural prescription

but require case by case weighing up of the factors involved.

The overarching question identified was 'how much and which safeguards and monitoring processes should be built into which stages of an IF model'. For example, how far should individual expenditure and choices be monitored to ensure compliance with legislation and processes for supported decision making, and is the latter a role that might be taken up the Office of the Public Advocate. Some participants suggested that too greater a focus on compliance and safeguards indicated a lack of trust within the system, would be too costly, would replicate previous overly bureaucratic system, or that perhaps governments and service providers were not committed to a transfer of power and were pulling away from a commitment to the underlying elements of IF.

### **Building Organisational and System Capacity**

Craig and Cocks' (2009) description of the reforms at Gawith Villa demonstrates the degree of cultural, organisational and workforce skill set change required to effectively implement individualised and inclusive day options. The approach of Gawith Villa had been to build the capacity of the organisation and equip staff with new skills with the shift to an IF model being the last phase of change. Participants highlighted the resources and energy that were needed to achieve organisational change and service development if IF is to work, and the importance of involving people with intellectual disabilities and their families in this change. IF models rely on a strong and effective supply side i.e. staff and organisations available from which to purchase support, to match demand generated by individual consumers. The combination of organisational systems and staff capacity were thought to be the most influential factors on IF outcomes. For people with intellectual disability it is these factors that are needed to promote and support people's informal connections to the community.

Attention was drawn to the fundamental change required in staff perceptions of their roles and the type of practice competences needed. In day programs, for instance, rather than organising group based activities staff are required to provide more 1 to 1 support but also to locate, negotiate and then facilitate opportunities for community involvement for people with intellectual disabilities, support community members to involved with people with disabilities, recruit and harness the energies of community volunteers, and build individual networks and circles of support. Many of these are long term tasks

which progress only slowly. Much more than previously the work of support workers is at two levels, firstly that of community capacity building (increase the ease with which people and organisations can include people with disabilities as part of their communities), and secondly supporting linkages into the community at the individual level. The new skill set for this type of work in disability is not yet well articulated, nor have either pre or in service training programs been realigned. Although it is noteworthy that key components are to be found in existing community development training programs. The further issue of staff supervision and quality monitoring was identified as a pressing issue. If people need support, the staff providing it need supervision and the question is 'how to supervise staff without intruding into the life or experiences of the person being supported'.

Many issues were raised about the potential dangers to service providers both government and non government in the shift towards IF. These included: extra costs of functions that fall outside their mandate, such as advocacy and independent support with decision making; need for much more frequent reviews of individual support and funding than is currently budgeted for; bearing the cost of crisis that occur for individual clients, and functions that are not funded at all such as staff supervision and mentoring. Participants emphasised that centrally struck pricing structures must give significant attention to the costs of organisational infrastructure that are fundamental to staff supervision and quality control. They pointed to the short term dangers of a market model driven by price where it appears clients could get more for their money by using services with fewer overheads or leaving out case management or specialist assessment costs, or trained/ supervised staff but inevitably it was suggested, this would be at the price of quality of support. This also related to the lack of recognition and commensurate levels of funding about the complexity of the practice involved in supporting people with intellectual disability to be involved in the community, and the sense that such skills are intuitive. However, both a recognition and clearer exposition of the skills necessary to promote cognitive, behavioural, communication and physical access will help avoid pressure towards use of untrained staff. Participants were also concerned that organisations would be forced to narrow their involvement with service users and be unwilling or unable to invest time into coordination and collaboration with others involved in the person's life. It was suggested that pricing structures might be such that organisations could not afford to offer support to people with more complex and changing support

needs. This issue goes back to the development of just and transparent processes for allocating funding to individuals, and the danger of funding caps placed on activities that do not match the real costs of supply.

The final issue raised was the necessity of capturing outcomes rather than outputs, and the value of using both qualitative and quantitative measures. Participants agreed that any approach to measurement should use objective quality of life indicators in conjunction with more qualitative data on individual outcomes, referenced back to the situation and goals of each individual, i.e. 'what was planned, did it happen and what was the outcome of this for the person's subjective and objective wellbeing'. An approach such as this can also double as a means of individual review and organisational quality control.

## Summary

IF models offer increased potential for people with intellectual disability to exercise choice and control over support they receive, which should lead to opportunities for greater inclusion in the community and control over their own lives.

IF has two components, matching funds to individual needs and individual control over funds.

IF is just one component of a disability service system, increased levels of funding to meet unmet demand, broader social change and community development are also required to achieve the current visions for the lives of people with disabilities encapsulated in current social policies.

The potential of IF can be undermined by a wide range of factors, including insufficient funding for identified needs, poor access to mainstream health and community services, lack of affordability housing and discriminatory community and institutional attitudes towards people with disabilities.

IF models must include multiple options for the control and management of expenditure by individuals to accommodate those who do not wish to exercise direct hands on control.

Access to mainstream health, housing, transport, education, leisure and community services and community infrastructure is critical to the success of IF. Various strategies can be used to achieve this, both specifically targeted on people with intellectual disability but also in conjunction with other disadvantaged groups who experience similar difficulties with access.

IF models must take account of the diversity of people with intellectual disability and their

social circumstances, in particular, differences in experiences, capacity to express choice, make decisions, differences in strength, composition and potential of informal social networks, differences in complexity of needs, differences in needs over time, and differences in need for external case management, coordination or monitoring and review and difference in geographic location.

A key challenge in IF it to devise mechanisms that support the maximum involvement of people with intellectual disability in exercising choice and decision making, which are sophisticated enough to recognise the diversity and differences in the nature, importance and complexity of decisions or choices to be exercised about a person's life and identify the different types of support required for different types of choice.

Mechanisms for supported or distributed decision making as well more formal substitute decision making are central to the implementation of IF for people with intellectual disability so the processes used for making the range of choices necessary in a persons life are transparent. This will safeguard against others exercising choices based on best interests or their own interests rather than the direct preferences of the person with intellectual disability, or clearly demonstrate that best interest choices have been made.

More so than may other groups people with intellectual disability will require funds to be devoted to self advocacy, case management, regular review and monitoring and an iterative planning process. Collaboration between all those providing support to a person is critical and recognition must be given to resourcing coordination or it will be threatened.

IF does not mean all support is based on one to one support, or that people cannot chose to be part of groups. IF does require all support to be carefully planned at the individual level. The processes of choosing an activity and its meaning to the individual rather than the activity itself should be the primary indicator of any outcome.

A distinction should be made between the different types of plans involved in IF models, and attention given to building individual networks of informal support or circles of support for all people with intellectual disabilities so that PCP to guide the broad goals for a person's life can occur and inform more formalised planning for the allocation and management of funding and support.

Formal planning must take account of the strength of a person' informal network and its capacity to drive the process, as well as a person's history of involvement with services.

People with high support needs are in danger of being disadvantaged when funds are disaggregated, and/or when funding levels are not high enough to take into account their need for support at all times. As a consequence this group are often reliant on sharing support with others, and thus more vulnerable than other groups to their choices being compromised and having reduced options for quality individual support, and social inclusion.

Funding levels must reflect the real cost of support to people with high or complex need to enable them to excise individualised choices if support if they wish. In the absence of this clear indicators must be provided about the basis of allocated funding level – does it reflect identified needs or personal aspirations.

Achieving a balance between accountability, choice and flexibility is critical in IF models. Too many controls and monitoring of expenditure, funding limitations may interfere or constrain with individual choice, and loose the advantage of flexibility and responsiveness offered by IF.

Fundamentally different skills are required of some staff in an individualised approach to support. Much more than previously the work of staff is at two levels, firstly that of community capacity building, and secondly supporting linkages into the community at the individual level.

Outcomes measure must be designed that taken into account subjective and objective quality of life indicators but also outcomes referenced back to the individual's own goal.

### **Plain English Summary**

- *IF should help everyone have more choices and more say in their lives*
- *IF has two parts: enough money for each person's needs; and each person has a say about how the money is spent.*
- *IF alone can't fix everything.*
- *There must be different ways to make IF work for different people.*
- *Everyone needs to work to make health, education and community services better – not just people with disabilities.*
- *People with intellectual disability may need help to make decisions.*
- *Having a choice is more important than what is chosen (as long as it's safe and legal)*
- *People with high support needs need more help. They shouldn't be left out of IF.*
- *Staff need different training to work this way.*

- It's important to have ways to check that IF is making a difference in people's lives.

## References

Bigby, C., & Fyffe, C. (2007). *Housing and support for people with intellectual disability and high, complex or changing needs*. Proceedings of the second annual Roundtable on Intellectual Disability Policy. School of Social Work and Social Policy, LaTrobe University.

Craig, K., & Cocks, E (2009). The journey towards inclusion and individualised funding – A case study of service reform. In Bigby, C & Fyffe, C. *Achieving their own lives: the implementation of individualised funding for people with intellectual disability, Proceedings of the third annual roundtable on intellectual disability policy*. Melbourne. School of Social Work and Social Policy La Trobe University.

Laragy, C. (2009). Does individualised funding offer new opportunities or unacceptable risks? Australian case studies of people with an intellectual disability. In Bigby, C & Fyffe, C. *Achieving their own lives: the implementation of individualised funding for people with intellectual disability, Proceedings of the third annual roundtable on intellectual disability policy*. Melbourne. School of Social Work and Social Policy La Trobe University.

Neely-Barnes, S., Graff, C., Marcenko, N., & Weber, L. (2008). Family decision making: Benefits to persons with developmental disabilities and their family members *Intellectual and Developmental Disabilities* 46(2), 93-105.

Ramcharan, P. (2009) Self administration ad direct payments? Self advocacy, circles, microboards ad brokers. In Bigby, C & Fyffe, C. *Achieving their own lives: the implementation of individualised funding*

*for people with intellectual disability, Proceedings of the third annual roundtable on intellectual disability policy*. Melbourne. School of Social Work and Social Policy La Trobe University.

Reinforce with Frawley, P. (2009) Self advocates views on individualised funding. In Bigby, C & Fyffe, C. *Achieving their own lives: the implementation of individualised funding for people with intellectual disability, Proceedings of the third annual roundtable on intellectual disability policy*. Melbourne. School of Social Work and Social Policy La Trobe University.

Stainton, T. (2009) Individualised Funding: An International Review of Approaches, Outcomes and Challenges. In Bigby, C & Fyffe, C. *Achieving their own lives: the implementation of individualised funding for people with intellectual disability, Proceedings of the third annual roundtable on intellectual disability policy*. Melbourne. School of Social Work and Social Policy La Trobe University.

Vizel, I. (2009) Individualised funding in the context of scarce resources and inaccessible housing markets. In Bigby, C & Fyffe, C. *Achieving their own lives: the implementation of individualised funding for people with intellectual disability, Proceedings of the third annual roundtable on intellectual disability policy*. Melbourne. School of Social Work and Social Policy La Trobe University.

Wilson, E., & Campaign, R. (2009). Problem solving, people skills, and personalised arrangements. Early results of research into individualised approaches for young adults receiving 'futures' funding at Scope. *Achieving their own lives: the implementation of individualised funding for people with intellectual disability, Proceedings of the third annual roundtable on intellectual disability policy*. Melbourne. School of Social Work and Social Policy La Trobe University.

# INDIVIDUALISED FUNDING: AN INTERNATIONAL REVIEW OF APPROACHES, OUTCOMES AND CHALLENGES

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## Introduction

Over the past 25 years or so individualised funding (IF) has gradually become part of the disability, and to a lesser degree, the intellectual disability policy, landscape in many jurisdiction throughout the world. Not surprisingly a variety of approaches have emerged with variations in target populations, age groups, levels of funding, comprehensiveness and support systems. There is to date limited research evidence on (IF) and what is available is often limited by its transferability to other jurisdictions due to variations in context or approach.

We do have some reasonable evidence from other user groups, primarily physical disability and this suggests that users are more satisfied with IF than with traditional models of funding supports (cf Glasby & Littlechild, 2002; Stainton & Boyce, 2001; 2004). There is also an increasingly strong body of research evidence to support the claim that IF/DP enhances both the control individuals and families feel over their own lives and the effectiveness of the support (Dawson, 2000; Lord and Hutchison, 2003; Powers et al., 2003; Rosenau, 2002; Stainton and Boyce, 2004), this is consistent with the large amount of anecdotal evidence from various jurisdictions.

One aspect of IF which to some degree sets it apart from other policy instruments is the degree to which it has developed into a cornerstone of emancipatory projects of various disability groups. This is most notable in the US 'Self determination movement' (cf <http://www.self-determination.com/>) but is also confirmed by research literature from other jurisdiction which notes the emancipatory terms which people use to describe their experience of IF (Stainton and Boyce 2004). It is therefore important to keep in mind that while on one level IF is simply a policy mechanism it is embedded in a discourse of rights, freedom and equality within the disability communities.

This paper seeks to explore some of the commonalities of experience between jurisdictions,

primarily Canada, the US and to a lesser extent the UK and Australia to highlight some of the common issues and challenges. It is hoped that by looking at cross jurisdictional issues we can identify what is common to IF implementation and what general approaches may be effective across these. We will begin by a brief look at definitions and variations and then explore some of the contextual issues regarding the supports and systems which surround IF. A brief review of the data on cost and resource will be followed by a brief look at some common challenges and problems as well as potential solutions will complete this review.

## Definitions & Models of IF

Although what individualised funding is seems straight forward enough, it is useful to consider definitions to distinguish it from other forms of funding such as income security or disability benefits. There is also a range of terminology in use which is not always consistent and often denotes variation in the policy or implementation. A good working definition can be stated as: funding allocated directly to an individual or in the case of a child their parents or legal guardian, to provide the support necessary to meet disability related needs and to assist individuals to become contributing citizens. IF has two fundamental characteristics:

*The amount of funding is determined by direct reference to the individual and/or family's specific needs, and aspirations; The individual and/or their family determine how funds are used to meet those needs eligible for funding. (TSC, 2002)*

The two aspects are important as the first speaks to determination of level and the second to control over how those funds are spent. In general most jurisdictions have more commonly done the former but the latter usually consist of at best a menu of preset service providers. The control over resources largely remains with the provider rather than the person or family denying them both a right of exit and contractual status. In short, the power and control remains with the funder and provider and most providers implicitly recognize that structurally it is the funder they are accountable to and whom they must satisfy in order to maintain their funding.

As noted there is a great deal of variation in models related to individualised funding. Some jurisdiction such as British Columbia make a distinction between individualized and direct funding, the former being when the individual or family administers the funds themselves including all payee, insurance and employment related task. Direct funding is used to denote when an agency is used to help administer the funding

though the person remains in decision making control. A third variation in BC is the microboard model where a small registered society (charity) is formed with the sole function of supporting a single individual (Vela, nd). These usually consist of the individual, family and personal network members. While their function is often more than simply administering funding and supports this is frequently a key role

In the US the term individualised funding is most commonly used but often described as part of a broader 'self-determination' model. The use of agents, or 'fiscal intermediaries' to administer IF is common but typically no distinction is made between this and direct administration. An interesting model which does not fully meet our criteria is the State of Illinois Home Based Support Services Program (HBSSP). This program serves adults with intellectual disabilities living at home with family. Families are allocated individualized funding of approximately US\$1656 per month [2005]. With the assistance of a service facilitator, they purchase goods and services to meet their unique family needs. Frequently purchased services include: respite, personal assistance services, home modifications, assistive technology, employment services, recreational services, therapies, and transportation (Heller & Caldwell 2005; Caldwell & Heller 2003). While the programme meets the key definitional requirement of control it does not meet the criteria around funding determination as the amount is generally fixed across users.

The UK of course has the cross group direct payments programme which serves all community care user groups'. In general direct payments are directly allocated to the individual or a trustee and the local authority usually funds a private or more commonly a voluntary body to provide administrative and other supports to users of direct payments. One recent variation is the introduction of personal and individual budgets.

*Personal budgets are an allocation of funding given to users after an assessment which should be sufficient to meet their assessed needs. Users can either take their personal budget as a direct payment, or - while still choosing how their care needs are met and by whom - leave councils with the responsibility to commission the services. Or they can take have some combination of the two.*

*Individual budgets differ from personal budgets in covering a multitude of funding streams, besides adult social care: Supporting People, Disabled Facilities Grant, Independent Living Funds, Access to Work and community equipment services (Samuel, 2008).*

A final model to note is when IF is embedded within a broader structure of support. Australia has pioneered an excellent example of this with its development of Local Area Coordination. This approach combines information, planning and community connection facilitation with small amounts of IF as a stimulant to more naturally occurring supports in the community (Bartnik & Chalmers, 2008).

## Context

IF of course rarely exist in isolation from other programme or policy initiatives. It has been argued that for IF to be fully effective in supporting the rights and self determination of individuals with intellectual disabilities and their families it must be embedded in a broader context of service and policy structures (Stainton, 2005, 2007). Three key areas have been suggested as important:

- support for people to articulate their claims
- support for people to identify, obtain and manage supports necessary to actualize their claims
- providing control over the resources (Stainton, 2007; 2005).

A fourth element which has more recently emerged is concerned with *governance*: that is, issues of who controls decision making within the system, not simply on an individual level, but on a broader structural level (Stainton, 2005).

In the first element, the concern is with issues of decision making and advocacy, but also with giving people information to make informed decisions. For IF to be an effective clearly people must be empowered and supported to make decisions. For many people with an intellectual disability the simple act of articulating what they want, and having that recognized by the system, can be problematic. This may be because they do not use formal communication methods or their right to express preferences and have them respected is suppressed through laws which declare them incapable. A good example of this is the 'willing and able' requirement in the UK Community Care (Direct Payment) Act 1996 which has been a major stumbling block for people with intellectual disabilities who wish to access direct payments.

If a person is unable to directly articulate their wishes, the question becomes; who is best placed to interpret and convey their wishes?' While Governments have been increasingly recognizing and supporting advocacy, including self advocacy (see DoH, 2001), they have been less keen to recognize the rights of advocates to the tools needed to effectively represent the interests of

<sup>1</sup>ID, mental health, older people, addictions and HIV/Aids

those they advocate for (Stainton, 2005). On the more formal side, many jurisdictions have been concerned with reforming their guardianship and related laws to provide options which do not involve an automatic loss of rights. This issue has also been recently recognized in the UN Convention on the Rights of Persons with Disabilities (2007):

*States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity (Art. 12 Para 3).*

Similarly the Montreal Declaration notes:

*People with intellectual disabilities should be supported to make their choices and decisions, to communicate them and to have them respected. Accordingly, where individuals have difficulty making independent choices and decisions, laws and policies should promote and recognize supported decision-making. States should provide the services and the necessary support to facilitate persons with intellectual disabilities in making meaningful decisions about their own lives. (WHO/PAHO, 2004)*

One of the most progressive pieces of legislation in this area is British Columbia's Representation Agreement Act 1996 which provides a simple, inexpensive means for individuals to formally recognize one or more persons as their representatives for routine health, personal care, financial decision making and legal affairs. The real innovation in this Act is its change to the way capacity is viewed and understood. Rather than a simple common law test of capacity to determine whether one can formally express an understanding of the meaning and consequences of a given decision, the Act relies on expanding the traditional concepts around communication and the nature and quality of the relationship. Section 3(2) notes that An adults way of communicating with others is not grounds for deciding that he or she is incapable of understanding anything referred to in sub-section (1). Section 8 of the act states:

- (1) An adult may make a representation agreement even though the adult is incapable of
  - a) making a contract, or
  - b) managing his or her health care, personal care, legal matters, financial affairs, business or assets.
- a) whether there is a relationship with the representative that is characterized by trust.

The three key shifts which are required are an expanded notion of communication and an

emphasis on the quality of the relationship (trust) between persons so that when people may not be able to traditionally communicate their choices, those best placed to interpret for them, i.e. those who know them best, are empowered to represent them and, recognition that incapacity is often a function of lack of support rather than inherent in the person. This is essential for individuals who cannot directly articulate their wants and needs if they are to avoid having them solely determined by professionals or formal guardians who have little knowledge of who they are as individuals and whose interest in them is structurally professional rather the personal.

The second element is concerned with supporting people to identify, obtain and manage necessary supports. 'Brokerage' type supports such as Local Area Coordination and person centered planning are two common expressions of this element. This generally requires a restructuring of current case management systems either through internal reform or by relocating these types of supports to the community (see Stainton 2007).

The third element, IF, is of course concerned with how the person's control over resources can be increased. Without the other elements however this control can be meaningless or in fact increase the burden on individuals and families if they are required to hire, managed and account for supports without support.

In British Columbia services have been restructured to a large degree along these lines. The existing service model was a fairly traditional case management model where Ministry social workers acted as both gatekeepers and support workers to families and helped them to access a range of direct government and contracted agency services. The entire system was devolved out of government to a crown agency with a board appointed by the Minister. The key to the BC model is the separation of the planning support<sup>2</sup> functions from eligibility and funding determination, along with a broad based introduction of individualised funding and changes to the community governance of the system. In order to achieve this, within a single entity, the structure divides these roles under two Vice Presidents (VPs), each reporting directly to the CEO, hence providing some degree of autonomy for each arm of the organization but ensuring a shared policy framework and a reasonable degree of cooperation within the organization as a whole. On the planning and support side, the majority of the former case managers are designated as Facilitators whose role involves:

<sup>2</sup>Note the role is described as planning support, indicating the role is not to plan for people but to support them and their networks to plan for themselves.

- Providing information and referral support;
- Providing help developing and implementing a plan and developing community capacity for informal and unfunded supports;
- Assisting with access to non-CLBC supports;
- Involvement as needed in crisis situations;
- Coordinating supports with MCFD and other children and family supports outside of CLBC;
- Providing support with life transitions for children, youth, individuals and families including assisting people with changes in existing supports;
- Ensuring people are linked to personal support networks. (CLBC 2005 p. 3)

The support is intended to be available as required, including ongoing monitoring if required. The Operations Analysts have the following responsibilities:

- Determining eligibility within policy guidelines;
- Evaluating and approving funding request based on individual plans and within policy and fiscal parameters. Request may come directly from individuals or via a facilitator-supported plan;
- Assisting coordination with other funded supports outside CLBC where required;
- Purchasing and monitoring service deliverables and accountabilities pursuant to contractual agreements and approved funded supports in individual plans (both individualized and block funding);
- Ensuring community capacity is developed for emergency/crisis response and monitoring the contract related to this work. (CLBC 2005 pp 2-3)

The planning function is intended to encompass the Person Centred Planning approach, now becoming 'best practice' in many jurisdictions (Holburn and Vietze 2002). This planning support role is intended to be broader than simply accessing services, and includes assisting individuals and families to access generic community supports and network development. The fundamental role of families and networks to act as advocates is also recognized formally in the CLBC model (CLBC 2005).

A final point concerns the governance of the model. The board by legislation must have a majority of persons who are either themselves intellectually disabled or are a family member or other person with a 'significant connection' to someone with an intellectual disability (BC 2004, Pt1. s.5). In addition the board must constitute an advisory body composed exclusively of persons with intellectual disabilities.

At time of writing the model is still being implemented and has not been without problems, some of which are discussed below, however it is one of the few examples of how IF is embedded in a broader structural context intended to maximize the promotion of rights and self determination of individuals and families who rely on the system<sup>3</sup>.

In the US numerous States have implemented IF in an array of models. In general the models involve an IF allocation based on a plan developed with the aide of a broker; these are usually in private practice chosen from an approved list, who also help to implement and modify the plan as required. The individuals or families also have access to financial and employment supports, again usually private, commonly known as fiscal intermediaries. In most cases these services are funded through an allocation attached to the individuals IF. A good example is the San Diego Regional Centre's My Life...My Way Project. Here again we can see the separation of planning and funding and eligibility determination and the embedding of IF within a context of supports designed to ensure maximum impact on self determination

(<http://www.selfdeterminationsandiego.org/main.html>

<http://www.dds.ca.gov/SDS/Index.cfm>).

## Cost and Resources

The evidence on cost and resource implication of IF is somewhat limited, particularly for intellectual disability. It is also complicated by the difficulty in estimating the opportunity and support cost of implementing IF. Below is a brief summary of the literature on cost and resources, given the paucity of data it includes data from other user groups which is indicated where applicable.

## United States

Two major sets of IF initiatives form the bulk of US programmes, Cash and Counselling (CC) which focuses on people with physical disabilities, chronic illness, children with developmental disabilities and seniors, and the Self-determination projects which focus on developmental disabilities. In each

<sup>3</sup>To follow the development of CLBC see: <http://www.communitylivingbc.ca/main.htm>

case they have operated in multiple States with significant variation amongst the programmes.

Conroy et al (2002) who focussed on ID and utilized comparison and control groups design. Results varied but in the three States reported on he found:

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

(<http://www.outcomeanalysis.com/DL/pubs/RWJ-SD-Final-Report.PDF>)

Rigorous control group studies were conducted on the Cash and Counselling initiative in Arkansas by an independent research body. The Arkansas project shows CC in the first year was more expensive than traditional methods but the authors note that the level of service was far higher in the control group. Despite this difference by year two the cost had reached relative neutrality. The authors conclude 'adopting a "Cash and Counselling" model of consumer direction can be a cost-effective way to substantially improve the access to care and well-being of people eligible for Medicaid personal care.'

([http://www.cashandcounseling.org/original\\_demonstration/download.html](http://www.cashandcounseling.org/original_demonstration/download.html))

The Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago, has conducted a control outcome study of the Home Based Support Services Program mentioned above. It was observed that individuals with disabilities enrolled in the family support program were significantly less likely than individuals with disabilities on a waiting list to move into an out-of-home placement. In addition they note a range of positive social, economic and health related outcomes for the families and individuals. This indicates significant cost savings to the State over time through a decrease in out of family placements which, as with most jurisdictions, are significantly more expensive. (Caldwell, J., & Heller, T. 2003; Heller, T. & Caldwell, J. 2005)

## United Kingdom

The literature on DP cost is limited and focuses mainly on physical disability, the primary user

group. Existing literature range from citing savings of 30%-40% on support packages (Zarb & Nadash, 1994) to more cautious estimates which suggests that DP may not result in cost savings, but that they 'certainly represent value for money' (Taylor in Glasby & Littlechild 2002). Dawson (2000) in one of the more comprehensive evaluations of a DP scheme concludes that DP is a cheaper alternative to direct service, and that the scheme should become cheaper still over time. She does note, however, the difficulty in estimating all the related costs such as opportunity costs to the local authority, and indicates that the approach used in the implementation can have a significant impact on the overall cost of such schemes. It should be noted that from the outset DP schemes were required to be 'at least as cost effective' as services otherwise arranged (DoH, 1997 in Glasby & Littlechild, 2002). A study of DP in two welsh authorities (Stainton, Boyce & Phillips, forthcoming) concluded that if implemented effectively, DP need not be any more costly than traditional services and may over time prove to be less costly. They also found evidence to suggest that considerable opportunity cost savings could be achieved with better policy, systems, training and procedures, along with a critical mass of users. This is consistent with other findings (Carmichael & Brown, 2002) which suggest that overly complex administrative procedures, a lack of critical mass, lack of training and experience among case managers, and a lack of effective support services hinder the take-up rate, effectiveness and efficiency of direct payments schemes.

In the most recent and comprehensive study of DP, the Personal Social Services Research Unit (Davey et al, 2007) surveyed all Local Authority direct payment and support scheme leads in the UK. Their findings indicate wide variation in implementation and cost, but overall found that direct payments were cheaper for learning disability (intellectual disability)(33-34). It should be noted that this is based the percentage of community care budget spent on direct payments for each group compared to the percentage of users on direct payments. As such it does not directly account for variation in intensity, type of support, etc. which may affect cost comparisons. For residential care cost, live-in direct payments were less expensive on average than comparable cost for residential care for all groups except older people and mental health (61). This study also notes that considerable variation exists across authorities and that comparison can be further complicated by the inclusion in DP rates of items such as: Tax; National insurance; Holiday pay; Sickness pay; Start-up costs; Contingency funds; and Support costs.

In summary, the majority of evidence across jurisdiction supports better outcomes (cost/benefit) with IF over conventional systems without significant cost differentials:

- US and UK evidence suggests that over a relatively short time cost of IF systems produce increasing cost savings and efficiencies, though in some cases IF is initially cost neutral or slightly higher;
- Cost savings are dependent on implementation structures and realizing savings elsewhere in the system (i.e. reducing case management over time rather than operating a double system)
- Research indicates indirect savings in areas such as health care utilization, crisis etc.

## Challenges and Issues

Enough Jurisdiction have introduced IF that we can begin to identify some of the challenges which come with trying to implement an IF system. Below we will briefly review some of these; though much of the evidence to date is anecdotal it is nonetheless worth a brief review.

Many of the challenges not surprisingly are associated with the transition from the current system to a model based more along the lines described above in the context section. As noted for IF to really be effective it must be embedded in a system which supports its use and one which is predicated on enhance the rights and self determination of the family or individual.

### IF in isolation of broader support and system change

The simple introduction of IF without any support mechanisms around planning, implementation and the fiscal aspects of managing ones own supports can in some cases add to the challenges that families face or exclude those who are not in a position to undertake these roles. To meet this challenge governments must ensure the planning, implementation and management supports are in place.

### Transitioning funding

One problem that many jurisdictions have faced is the issue of unbundling funds from the current system to an IF model. Most services are predicated on a certain number of persons using the service and it is not simply a case of reducing the funding for a group home if a single person decides to move to a self managed arrangement using IF. This problem is more acute when services do not identify specific individuals associated with a funding stream but

simply contract to provide X service for a specific numbers of eligible individuals. This problem is less acute when transitioning from institutional services where the intent is to close the former service. For this reason a direct transition to IF from institutions is the preferred method rather than transitional steps to group homes etc... Other options to mitigate this challenge include some form of transitional funding for services when an individual moves to an IF system and some overhead/admin cost (service cost would come through IF) for established agencies to ensure necessary administrative cost are consistently covered. It is also useful for systems to require any funding to be attached to a specific individual rather than a block contract as this will make unbundling easier but also create a more person centre focus for the current service.

## System Inertia

Transitioning to a new model will always create certain anxieties, and occasional resistance for those invested in the current system both on the state and agency side. Careful planning and good communication can mitigate this to some degree but it is important to be aware that a period of transition will be required before the new system will be effective.

## Unionized Environments

A number of challenges can arise in unionized environments both with regards to system changes which may replace or eliminate some jobs in the State sector or when traditional services are replaced by individualised supports managed directly by the person. Again, careful and respectful planning along with good communication is essential here. While planning and other roles in the State or contract sector are not incompatible with unionization, it is unlikely that individually managed direct care staff will be compatible with unionization. A strong set of controls on employment regulations, health and safety, and wage ranges (with a commitment to fund IF at levels which allow for comparable wages) can mitigate the challenges presented by unionized environments.

## Staffing

A number of issues arise related to direct support staff. Clear guidance is needed with regards to the requirements of IF users to comply with employment standards and obtain requisite insurance. This is usually included in the IF package or in some cases a global plan is provided which user can sign on to. Clear guidance is also required around the hiring and payment to family members. Most jurisdictions have prohibitions

against hiring family members living in the same household, though there are exceptions, particularly in the case of children or when the relative is the best person available and the alternative is a foster or residential care option which inevitably cost the state more and is less desired by the individuals involved.

Hiring and contracting with staff can also be problematic for families and individuals if they do not have experience or, from a safety perspective, do not want to disclose too much personal information during recruitment. Many DP support programmes offer support for developing contracts and sometimes provide interview venues or support if desired. Some also retain a roster of staff from which perspective users can choose interviewees who will usually have police checks and often some basic training or qualifications.

Other staffing issues include the issue of training for staff. Many people are not particularly concerned about qualification but may require support staff to have some specific training such as seizure management. Again, some support organizations may offer generic training or assist in obtaining relevant training for the support staff.

An emerging issue in some jurisdictions is serious support staff shortage. This is usually related to pay levels so funders need to ensure that IF allocations allow for realistic salary levels within the persons area.

Finally, staff cover for emergencies or unexpected contingencies such as staff sickness or holidays can be problematic as they often do not have the roster of staff an agency may have. Many people develop their own roster of 'on call' staff but where this is not the case a back-up is required. One option which has been used successfully is for the government or a support agency to contract with a care agency to provide short notice care for IF users.

### **Decision making-recognition of representatives**

One of the big challenges in implementing IF for people with intellectual disabilities involves decision making and ability to contract. Many people with intellectual disability will require assistance to manage IF lack of a personal network to assist or have lost the right to contract. The answer to this challenge is not simple nor is it always within the purview of the State agent responsible for intellectual disability services. On the one hand progressive decision making legislation like the Representation Agreement described above is an important part of meeting

this challenge. System like trust or microboards can also help mitigate this problem. The more complex problem is of course building personal networks so that individuals have trusted advisors around them who can interpret their wants and needs and are willing to help manage their supports with IF. Until this is in place, some form of direct funding with support to manage IF will likely be required.

### **Ideological challenges**

A final challenge needs to be noted regarding whether IF and a system based on rights and self determination is even desirable. Critics have argued that IF is simply an expression of liberal individualism and consumerism (Burton & Kagan 2006; Spandler, 2004). The question is of course if it is not the individual and their personal networks who are to control their lives, whom? The history of services and supports is littered with good, and not so good intentions on behalf of this population, perhaps its time we gave them a chance to determine their own futures. IF is one step along that road.

### **References**

- Bartnik, E. and Chalmers, R. (2008) It's about more than the money: Local area coordination supporting people with disabilities in Susan Hunter and Pete Ritchie eds. *Co-Production and Personalisation in Social Care Changing Relationships in the Provision of Social Care*. London: Jessica Kingsley. 19-38.
- British Columbia (BC) (2004) *Community Living Authority Act*.
- Burton, M. & Kagan, C. (2006) Decoding *Valuing People, Disability & Society*, Vol. 21, No. 4, 299 – 313.
- Caldwell J. & Heller T. (2003) Management of respite and personal assistance services in a consumer-directed family support programme, *Journal of Intellectual Disability Research*, Vol. 47 No. 4/5, 352-366.
- Carmichael, A. & Brown, L. (2002) The Future Challenge for Direct Payments, *Disability & Society*, No. 17, 797-808.
- Community Living British Columbia (March 2005) *Transforming Community Living Services in British Columbia*, (Vancouver: CLBC).
- Davey, V., Fernández, J.-L., Knapp, M., Vick, N., Jolly, D., Swift, P., Tobin, R., Kendall, J., Ferrie, J., Pearson, C., Mercer, G. and Priestley, M. (2007) *Direct Payments: A National Survey of Direct Payments Policy and Practice*, (London, PSSRU).
- Dawson, C. (2000) *Independent Successes: Implementing Direct Payments* (York, Joseph Rowntree Foundation).

- Department of Health DOH) *Community Care (Direct Payments) Act 1996 Policy and Practice Guidance*.
- Glasby, J. & Littlechild, R. (2002) *Social Work and Direct Payments* (Bristol, Policy Press).
- Heller, T. and Caldwell, J. (2005) Impact of a Consumer-Directed Family Support Program on Reduced Out-of-Home Institutional Placement *Journal of Policy and Practice in Intellectual Disabilities*, Vol. 2 No. 1, 63–65.
- Holburn, S. & Vietze, P. (2002). *Person Centred Planning: Research, Practice and Future Directions*. (Baltimore: Brookes).
- <http://www.dds.ca.gov/SDS/Index.cfm>  
<http://www.selfdeterminationsandiego.org/main.html>
- Lord, J. and Hutchison, P. (2003) Individualized Support and Funding: Building Blocks for Capacity Building and Inclusion, *Disability & Society* No. 18, 71–86.
- MCFD (2002) *A New Vision for Community Living: A Vision of Choice and Change*. Report of the Community Living Transition Steering Committee. (Victoria: Ministry of Children and Family Development).
- Powers, I., Sowers, J. and Singer, G. H. S. (2003) A Cross Disability Analysis of Person Directed Long-Term Services. MS. Portland: Centre for Self Determination.
- Rosenau, N. (2002) 'Individual Funding: Flavour of the Day or Sea Change?'. Policy Research Briefs, paper 2. Fitzroy: Disability Foundation of Australia.
- Samuel, Mithran (2008) Expert guide on direct payments, personal budgets and individual budgets accessed at <http://www.communitycare.co.uk/Articles/2008/08/12/102669/direct-payments-personal-budgets-and-individual-budgets.html> 07 Oct. 2008.
- Spandler, H. (2004) Friend or Foe? Towards a Critical Assessment of Direct Payments. *Critical Social Policy*, Vol. 24, No. 2, 187-209
- Stainton, T. & Boyce, S. (2001). *Final Report: An Evaluation of Cardiff and the Vale Independent Living Scheme and the Implementation of Direct Payments*, (Wales Office of Research and Development in Health and Social Care, Cardiff).
- Stainton, T. (2005) Empowerment and the architecture of rights based social policy, *Journal of Intellectual Disabilities* Vol. 9, No.4, 287-296.
- Stainton, T. and Boyce, S. (2004) 'I Have Got My Life Back': User's Experience of Direct Payments. *Disability and Society*, Vol. 19 No.5, 443-454.
- Stainton, T., Boyce, S. & Phillips, C. (forthcoming, 2008) Independence Pays: A Cost And Resource Analysis Of Direct Payments In Two Local Authorities, *Disability & Society*.
- Stainton, T. (2007) Case Management in a Rights Based Environment: Structure, Context and Roles in *Issues in Case Management Practice for People with Intellectual Disabilities: A Handbook for Practitioners*. Christine Bigby, Chris Fyffe and Elizabeth Ozanne eds. (London, Jessica Kingsley), 89 - 117.
- Transition Steering Committee (TSC) *Final Report & Recommendations: Individualized Funding & Planning Options Working Group*, Tim Stainton, Chair. British Columbia, September 28, 2002.
- United Nations (2007) *Convention on the Rights of Persons with Disabilities*.
- Vela Micoboards (ND). 'What is a Microboard' accessed at:  
[http://www.microboard.org/what\\_members\\_do.htm](http://www.microboard.org/what_members_do.htm) Oct. 7, 2008.
- World Health Organization/Pan American Health Organisation (2004). *Montreal Declaration on Intellectual Disabilities*. WHO/PAHO.
- Zarb, G. & Nadash, P. (1994) *Cashing in on Independence: Comparing the Cost and benefits of cash and service*, (BCODP, London).

# DOES INDIVIDUALISED FUNDING OFFER NEW OPPORTUNITIES OR UNACCEPTABLE RISKS? AUSTRALIAN CASE STUDIES OF PEOPLE WITH AN INTELLECTUAL DISABILITY

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Following international trends, the use of individualised funding is increasing within the Australian disability sector, with widespread support from disability advocates (Victorian Disability Advocacy Network, 2008). The hope is that individualised funding will give greater control and self-determination to people with a disability, and it will create new opportunities to realise individual potential, including people with an intellectual disability (Victorian Disability Advocacy Network, 2008). The Australian aged care sector is following this lead and is also considering its introduction (Laragy & Naughtin, 2008; Productivity Commission, 2008). There is increasing evidence that individualised funding results in positive outcomes, but more detailed knowledge is required regarding its impact on specific groups of people. This paper contributes to this knowledge by reporting in detail on two individualised funding studies I conducted in Victoria; and comparing the findings with interviews undertaken in Queensland, the United Kingdom and Sweden, and with published findings from three Victorian Government Disability Services' project evaluations where I was involved as an evaluator or an administrator.

## Individualised Funding

The term 'individualised funding' has different meanings in different locations. While there is always an assessment of need that determines an individual allocation of public funds, mechanisms to support people with intellectual disability to make decisions and manage funds, and the rules governing their use vary greatly. Some projects allow funds to be used flexibly to buy equipment, participate in social activities or employ support workers, while others restrict their use to employing support workers. Even when funds are restricted to employing support

workers, there are different structures for their use. Ungerson and Yeandle (2007) identified three ways of employing support staff in Europe (referred to as 'consumer directed care'). These are:

- funds held by the person to employ support workers from all sources including informal networks (family, friends and neighbours)
- funds held by the person to recruit and manage support workers from the open labour market, but not from family
- funds held by a service provider

Australian individualised funding projects have been categorised similarly and have two special features (Fisher & Campbell-McLean, 2008). First, recruitment of family members is generally not encouraged and sometimes not allowed. Second, some projects require that support workers be engaged from approved service providers and not recruited from the open labour market.

In Victoria, some projects allow people to recruit support workers, but they all have to be employed through an approved disability service. Funds are portable, which gives people the option of changing provider if preferred. Furthermore, individualised funds can be used flexibly as long as spending is in accord with an agreed plan (Department of Human Services, 2008). Funds can be used for attending disability services, community participation and buying equipment in addition to employing support workers.

The drivers for the introduction of individualised funding in Australia are similar to those elsewhere with people wanting more control and greater options; dissatisfaction with the limited range of services provided through traditional service provision; and governments hopeful that cost efficiencies will counter the rising level of unmet need and escalating costs (Commission for Social Care Inspection, 2008; Forder, 2007; Social Care Institute for Excellence, 2007).

## International

A brief overview of individualised funding in Sweden and the United Kingdom is provided because findings from interviews conducted by the author in these areas are compared with the Australian findings.

In Sweden, 1994 legislation (*Certain Functional Impairments*, known as 'LSS') gave people with all types of disabilities less than 65 years a legal entitlement to individualised funding to purchase support and live independently (Swedish Institute, 2000). A 'trustee' (Överförmyndare) is appointed by the courts to make decisions on behalf of

people with an intellectual disability who have limited decision making capacity. The trustee, who is often the person's mother, makes decisions regarding the use of funds and other significant life decisions. A range of management options exists that provide varying levels of control. Only 3% of people take full control and directly employ their own staff, mostly people with a physical disability (Interview with cooperative JAG, 2006). Others allocate their funds to organisations that become the legal employer of support workers. Twelve per cent of people join a cooperative; 25 per cent purchase supports from disability services (not-for-profit agencies and private companies); and 60 per cent transfer their funds to the local authority, which provides rostered support workers. These options indicate decreasing levels of direct control and more reliance on the agency.

In the United Kingdom, the *Community Care (Direct Payments) Act 1996* gave people with all types of disabilities the right to Direct Payments following a needs assessment. Direct Payments could only be used to employ support workers and the person, or their representative, was responsible for managing the accounts. A comprehensive history of Direct Payments and its more flexible successor, Individual Budgets is provided by Riddell et al. (2006). There has been a trend over time to allow allocated funds to be used more flexibly. In Control, is one of the not-for-profit organisation piloting Individual Budgets and it allow funds to be spent on 'anything' as long as it is not illegal or gambling (in Control, 2008).

The uptake of individualised funding in its different forms has been expanding rapidly and is greater in England than in the other UK countries. In 2007, 54,000 English people were using Direct Payments and 1000 were using Individual Budgets (Commission for Social Care Inspection, 2008). An independent evaluation of Individual Budgets is underway and the results are expected later in 2008 (Individual Budgets Evaluation Network, 2007).

The English Social Care Institute for Excellence (2007) provides a useful meta-analysis of current findings from individualised funding projects and concluded that they have been overwhelmingly successful in terms of enhancing choice, autonomy, empowerment, outcomes and satisfaction. No evidence was found of fraud or abuse of vulnerable people was reported. However, the evidence was inconclusive with regard to costs efficiencies and quality assurance and equity. Furthermore, the report did not comment on strategies for ensuring that the 'voice' of people with an intellectual disability is included in decisions.

## Australia

The 1988 Western Australian Local Area Coordination (LAC) program was the first large scale individualised funding program in Australia (Disability Services Commission, 2003). This was established to support people with intellectual disability, and later expanded to include people with all types of disabilities. Coordinators are responsible for a specific geographical area and use their local knowledge to assist with planning and organising supports and activities. Funding can be used flexibly to purchase personal support, goods, leisure activities or household help.

The Western Australian Disability Services Commission (2003) conducted a meta-analysis of 17 separate evaluation studies of the LAC program. The analysis reported positive findings, including for people with intellectual disability. People had more choice and control, and they gained more customised and diverse supports to meet their needs. The report did not identify any special supports for people with an intellectual disability, but coordinators were directed to focus on the person concerned rather than their family, "... the consumer is the central decision maker in determining the sorts of supports and services that they want to meet their needs as they see them, and in matters concerning their own lives" (p. 43). Key factors contributing to positive outcomes were positive relationships between the coordinator and 'consumers', and having one point of contact to gain information and support. While positive outcomes far outweighed the negative, limiting factors identified were: placing too much reliance on the personal abilities of the coordinator; some coordinators being too controlling and not informing people of the available options; coordinators not understanding people from Indigenous and culturally and linguistically diverse (CALD) backgrounds; workloads being too high; and inadequate financial resources.

In New South Wales, ten people with physical disabilities recently trialled 'direct payments' where they were allowed to employ their support workers (Fisher & Campbell-McLean, 2008). Using a control group, the evaluation found that the outcomes from using 'direct payments' were overwhelmingly positive. People using direct payments had higher feelings of personal wellbeing; a greater sense of control over their lives; more choice and a greater range of activities; better physical health; and improvements in pain and physical risk management. People with an intellectual disability, however, were not included in this project.

In Queensland, small agencies were established approximately 20 years ago with Commonwealth funding to support people use individualised

funding. It appears that few have been created subsequently. The State government now manages disability funding and has discouraged individualised arrangements.

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

The evidence available to date indicates that individualised funding has provided more opportunities for people with an intellectual disability, but the evidence is mixed as to whether it leads to more neglect or abuse (Fyson & Kitson, 2007; Social Care Institute for Excellence, 2007). As many projects are relatively new, problems may not have become evident. Concerns have been raised that individualised funding projects are dominated by people with a physical disability and the needs of people with learning difficulties may be neglected and their 'voice' may not be heard (Askheim, 2005; Bigby, Fyffe, & Mansell, 2006; Fyson & Kitson, 2007; Mansell, 2006). Furthermore, there are questions as to whether individualism has gone too far and the most vulnerable may be left without support in a market economy. Will market driven services ignore the marginalised who are unlikely to provide a profit? Will people be left isolated and vulnerable at home if there is no case manager to notice inadequate resourcing and no one to advocate on their behalf (Brennan, 2006; Gauthier, 2006; Knapp, 2007).

These complex questions will require studies in different contexts to distinguish any inherent limitations of individualised funding from contextual factors. Because the studies reported on in this paper come from different locations, they provide a valuable contribution to answering these questions. The specific research questions examined in this paper are listed below.

### **Research Questions**

1. Why are people with an intellectual disability using individualised funding?
2. What supports are provided to person with an intellectual disability to make planning decisions?
3. What mechanisms are available to provide information; support planning; and support financial accountability requirements?
4. What outcomes have been achieved?
5. Does individualised funding place people with an intellectual disability at greater risk compared to agency based service provision?

### **Methodology**

Data gathered in my studies of two Victorian projects and interviews in Queensland (2008), Sweden (2006) and the UK (2005) have been analysed to answer the research questions listed above. All studies were conducted with ethics approval from La Trobe University. Ethics approval for the studies in Sweden and the UK was limited to advocates, administrators and researchers and did not include people with a disability or their families. However, people from these categories were interviewed when they held formal positions (see Table 1 for interviewee details). Interviewees were recruited in Queensland, Sweden and the UK using 'snowball' sampling (Sarantakos, 2005), with the assistance of researchers and disability advocates in the places visited. The methodology used in the two Victorian studies and a description of each project is detailed below.

Semi-structured interviews were conducted in all interviews. The interview schedule was adjusted to circumstances and not all questions were asked of each person. Questions concerned the interviewee's experience with individualised funding; organisational structures; assessment, planning, allocation and accountability processes; supports available; the supports available to people with an intellectual disability to decide their lifestyle; quality assurance processes; adequacy of funding; outcomes achieved; community inclusion; risks; difficulties encountered; and theoretical perspectives and principles underpinning the project. Notes taken in all interviews were later carefully examined for themes, outcomes and issues.

The findings are compared with published findings from three Victorian Government Disability Services' project evaluations where I was involved as an evaluator or an administrator: *Futures For Young Adults* (Laragy, 2002); *Support & Choice* (LIME Management Group, 2005); and *Direct Payments* (LDC Group, Dimitriadis, Laurie, Lane, & Lyall, 2007).

While each of the studies has its limitations, the findings can be reviewed collectively to provide a comprehensive overview of the opportunities and limitations of individualised funding projects.

### **Individualised Funding Project (IFP)**

The *Individualised Funding Project* (IFP) was auspiced by UnitingCare Community Options (UCCO), a Victorian, not-for-profit church-based organisation. The Victorian Government allowed families receiving a *Making a Difference* 'package' through this agency to self-manage the \$5,000 allocated per annum in 2003. This 'package' was only available to families responsible for a family member with a disability. Over time the eligibility

Table 1. Interviews in Australia, Sweden, England and Scotland			
Location	Agency	Category of participant interviewed	No.
Australia VIC 2008	Karden Disability Support Foundation, Ballarat	Executive Officer	1
		Mother	1 (2)
Australia QLD 2008	Queensland Advocacy Inc. Brisbane	Director (physical disability)	1
	Lifestyle Options Inc. Brisbane (Funding pooled among members)	Board member (physical disability)	1
		Coordinator	1
	Homes West Association Inc. Brisbane	Father of young woman with severe intellectual & physical disabilities	1
		Coordinator	1
	Community Resource Unit Inc. Brisbane	Project worker	1
		Project worker	1
	Avenues Lifestyle Support Assoc. Inc. Gympie	Manager	1 (8)
Australia VIC 2007	'Outcomes' evaluation 2007, Individualised Funding Project: A project conducted by Uniting Care Community Options (Laragy, 2008)	Parents managing flexible funding on behalf of family member	7
		CEO and senior manager	2 (9)
Sweden 2008	Lund University	Academic - aged care	1
Sweden 2006	Cooperatives: Stockholm and Jönköping (4)	Coordinators	4
	Cooperative Jönköping	Personal support workers	2
	Municipality Jönköping		
	Municipality, Jönköping	Administrators (1 used individual. funding to care for dying son)	2
	National Social Insurance Office administrator (Försäkringskassan), Jönköping	Administrators	2
	Jönköping University	Researcher (previously local authority disability manager)	1
	County Council	Senior executive, Retired	1 (13)
England & Scotland 2005	Centres for Independent Living (6 centres: Derbyshire, Edinburgh, Glasgow, Leeds, North Somerset, West Sussex)	Coordinators (3 with physical disabilities)	6
		Disability advocates	6
	County Council and Local Authority (4 areas Edinburgh, Leeds, North Somerset, West Sussex )	Administrators and case workers (1 used individual. funding to care for son with extreme intell. & physical disabilities)	7
	Universities (Brighton, Bristol, Glasgow, Leeds)	Researchers (1 used individ. funding to manage mental health problems)	5
	Service provider (Edinburgh)	Senior managers and Board member with physical disability	3 (27)
		<b>TOTAL</b>	<b>59</b>

criteria for the project broadened, the numbers of people involved increased and there were significantly larger amounts of money involved. Families contributed to the project's policies and they managed their allocated funds, which could be used flexibly to purchase personal support, buy equipment and participate in community activities. I evaluated the establishment of the project using action research methods in 2003, with ethics approval from The University of Melbourne and oversight from a steering committee of families. Twelve families and two senior managers were personally interviewed and policy planning meetings were observed. In eleven of the families, a family member had an intellectual disability. This person was included in the interview process whenever that was practical and meaningful, and eight of the twelve family interviews included discussions or meetings with the person receiving services.

In 2007, seven of the original families who gave consent for follow-up telephone interviews, and personal interviews were conducted with two senior managers. One family member receiving supports had a physical disability and all others had an intellectual disability. Two detailed reports are available (Laragy, 2004, 2008).

### **Victorian Case Study**

A Victorian case study was conducted in 2008 at Karden Disability Support Foundation Inc (KDSF) in Ballarat, Victoria. The agency was established in 2006 to provide individualised disability supports. The Executive Officer was interviewed in her Ballarat office, and the mother of an 18 year male being supported to live independently was later interviewed by telephone.

### **Findings**

Table 2 provides a summary of the key interview findings from all studies, and findings from the two Victorian studies are detailed below.

#### **1. Why are people with an intellectual disability using individualised funding?**

##### **Victorian Individualised Funding Project**

Four of the seven families used individualised funding exclusively, two had a combination of individualised funding and case management, and one used case management exclusively. Families chose individualised funding to have control, use funds in flexible and creative ways and to avoid paying case management fees. Their previous experiences with case managers had ranged from positive to negative, and only some case managers worked cooperatively, shared information and were creative. Families who

retained a case manager did so to gain support, advice and access to alternate sources of funding.

Families using individualised funding said:

*"I want control .. to set priorities and be responsive to changing circumstances, ..*

*to know how much money I have and what I can spend until the end of the year."*

*"Doing our own case management is better because we have full control. The*

*difference is having knowledge and having control."*

*"We have had lots of things we would never have thought of when we depended*

*on the case manager. I want control over funding to use in flexible and in*

*creative ways... and flexibility with staffing."* (Laragy 2008:6)

### **Victorian case study**

The 18 year old male had severe autism, an intellectual disability, he was non verbal and he had an estimated intellectual age of 18 months. He attended a disability special school and respite services until he was excluded when 11 years old because of his violent behaviour. On his last day at school seven adults were needed to hold him down. He lived with his mother and two younger siblings, and there was considerable disruption to the whole household because of his behaviour. In mid-2006 he was allocated an individual budget to purchase 24 hour support. This was an alternative to disability residential services, where his mother expected he would have been heavily medicated to manage his behaviour.

### **2 What outcomes were achieved?**

#### **Victorian Individualised Funding Project**

New opportunities resulted from flexible funding. These included participation in clubs and community activities, attending a gym, attending a camp with a sibling, attending a neighbourhood house for activities instead of a disability day centre and *"keeping an eye out for anything that is of interest."* (Laragy, 2008:15)

Individualised funding did not however overcome all difficulties; inadequate funding and no available respite were major concerns for most families. While all self-managing families were highly satisfied with outcomes achieved, they all spoke of the difficulties and demands of accessing information about services and community opportunities.

#### **Victorian case study**

Supports were tailored to meet this young

**Table 2. Summary of key interview findings from studies undertaken**

	Victorian Individualised Funding Project (Laragy, 2008)	Victorian case study (2008)	Queensland (2008)	Sweden (2006)	UK (2005)
Why using individualised funding?	Greater control Greater range of services Access to more funds Enhanced quality of life*	No other services available	No other services available	Community living Enhanced quality of life Select own workers	Greater control Greater range of services Enhanced quality of life Select own workers
Outcomes achieved?	Greater control Greater range of services Access to more funds Enhanced quality of life	Less violent outbursts Community living Enhanced quality of life – for young man – for family Easier recruitment support workers	Community living Greater control Greater range of services Enhanced quality of life	Community living Enhanced quality of life Select own workers Access employment	Greater control Greater range of services Enhanced quality of life Select own workers
Support structures for information, planning, & financial accountability	Information difficult to access Planning workshops successful Financial accountability managed by agency for 10 % fee	3-monthly planning meetings at agency Financial accountability managed by agency for less than 10 % fee	Available through supporting agency	Variable:- High from cooperatives Low if self-managing	Variable:- – high from centres for independent living
Supports to involve person with ID in planning?	No formal mechanisms	Essential Lifestyle Planning used comprehensively	Variable, but person centred planning widely used	No formal mechanisms	Variable, person centred planning widely used in some areas

man’s needs in ways that were not possible in traditional services. Behaviour management and communication programs were developed when he was five years old, but they were never fully implemented until support staff were trained in his communication style before they entered his home. A transition program assisted him to gradually move into his own flat. A team of five or six support workers has supported him home 24 hours a day in his own for the past two years. It is noteworthy that some staff have continued throughout this period and recruiting new workers has not been a problem. This contrasts sharply with the refusal of staff to work with him previously.

The young man’s quality of life radically improved after his supports were individually tailored. His violent outbursts reduced in intensity and frequency from many in one day to a few in a year. With support, he undertook a wide range of activities including shopping and domestic chores like cooking and cleaning. Employment opportunities were being explored for him to deliver papers. His mother reported that family relationships improved immeasurably: she enjoys her role as mother instead of controller, and she has pursued her own career and worked full-time. His younger brother will have a ‘gap’ year in 2009 and part of this will be working as a paid worker in his brother’s home to re-establish their relationship.

### **3. What mechanisms are available to provide information; support planning; and support financial accountability requirements?**

#### **Victorian Individualised Funding Project**

All self-managing families were sponsored by the agency to undertake person centred planning and other courses, which assisted them develop plans for their family member. Three of the four self-managing families were happy with this arrangement, but one would have liked more support. No family took up the offer to purchase case management support. Families were satisfied paying the 10 per cent non-negotiable fee to the agency for account keep and a monthly statement.

#### **Victorian case study**

The agency supporting this young man was established in July 2006 specifically to provide individually tailored services to people with all types of disabilities. By July 2008, it had 58 staff and supported over 50 people living at home as well as two socialisation groups.

A contract was negotiated between the agency and each person, or their representative, which detailed the services to be provided and costs involved. In the month of June 2008, 89.3 per cent of the money received was used to pay support workers and their team leader's salary, superannuation, training and WorkCover costs; 7.8 per cent was spent on rent, office overheads and the salaries of the executive officer and one administrator; and 2.9 per cent was spent on client expenses for items such as a microwave. The agency established individual accounts from its inception and provided financial statements as people preferred: monthly, six monthly or not at all.

Support workers and team leaders were recruited by the agency because of their personal qualities rather than their disability qualifications. Disability training was available and Certificate 4 in Disability Work classes were available to support workers one day per week at the agency. Workers were paid for their time attending classes and they completed assignments in their own time.

The agency's policies and procedures were largely shaped by the executive officer. She holds a Certificate 4 in Disability Work, has extensive experience working as a support worker; holds a Masters of Business Administration; and at the time of the interview was undertaking a Masters in Disability. The agency was chosen by *Commerce Ballarat* as the best new business in 2007.

The young man in this case study was their first client. His mother gave excellent reports of the information and support provided by the team leader and the executive officer. Initially the mother was fearful because previous disability services had rejected her son. She took a 'hands on' role and participated in interviews for new support workers until she developed confidence in the agency when she saw that the arrangements were working well. She gained 'peace of mind' from knowing that she could exercise control if need be, and ultimately move to another agency. "Having control means I can let go of fear" (Mother).

### **4. What supports are available to people with an intellectual disability to decide their lifestyle?**

#### **Victorian Individualised Funding Project**

Parents contributed to the project's design, but there were no mechanisms for including the views of the family member with a disability. Many families were caring for young children or a family member with a severe intellectual disability and it would not have been appropriate to seek their opinions. However, this did not apply to everyone and one young man as a physical disability and attended university. For individual planning, parents were sponsored to attend person centred planning workshops. These were effective in teaching parents how to 'think outside the square' and finding creative ways of meeting needs. However, there was no indication that mechanisms have been proposed to enable those with a disability to participate with their parents in decision-making.

#### **Victorian case study**

The agency used Essential Lifestyle Planning (ELP) processes to promote the inclusion of the person concerned in decision making. People with a physical disability took direct control and those with an intellectual disability were supported to take as much control as possible, with the assistance of others as appropriate.

Because the young man in this case study became distressed easily, his family and workers decided that it was not in his interests to attend planning meetings. Planning and review meetings were held every three-months and they included his mother, siblings, representatives from other services that worked with him, former staff who maintained a relationship with him and his current support workers. Each attendee completed a planning worksheet that directed them to consider the young man's welfare and quality of life through questions such as, "How can he best participate

in the planning process; How do we ensure the planning process is respectful to him; What are his future hopes & dreams?"

## **5. Does individualised funding place people with an intellectual disability at greater risk compared to agency based service provision?**

### **Victorian Individualised Funding Project**

There was no indication of the family member with an intellectual disability being at any risk because their parents were self-managing. All parents sought out information, ensured that their sons and daughters socialised and were engaged in a wide variety of activities. Furthermore, agency staff were in close contact with families in the pilot project and had knowledge of each family circumstances. However, if the project expands greatly this close oversight would probably diminish.

### **Victorian case study**

The risks faced by this young man reduced when he moved to individualise funding. His previous behaviour had been extremely violent, placing himself and others at risk. His mother reported that his quality of life improved greatly after supports were tailored to meet his needs. There were multiple factors that provided a safety net for this young man. There was close oversight from his family and the agency through the team leader's supervision of support workers and three-monthly planning meetings. Additionally, ex-workers and others attended planning and review meetings. It seems unlikely that any risk factor would emerge that would go undetected for long.

### **Discussion**

The strength of this paper is that it provides in-depth insights into peoples' experiences of individualised funding. The limitations are that the number of people involved is small and nearly all took active steps to ensure they could use individualised funding. Consequently, the sample is not representative of all people with a disability and their representatives and the findings cannot be generalised. However, an examination of the mechanisms used to support people using individualised funding in different settings does provide a valuable contribution to the information available as the number of individualised funding projects continues to grow.

My studies were unambiguous in showing that many people with disabilities want more independence, control and a greater range of opportunities than was available through

traditional agency based services. In Australia, the Victorian case study and the Queensland interviews revealed that people moved to individualised services when no other alternatives were available. Whether moving to individualised funding through necessity or choice, all interviewees emphasised that the increased flexibility and control resulted in quality of life improvements. These findings are consistent with the Victorian reports on *Futures For Young Adults* (Laragy, 2002); *Support & Choice* (LIME Management Group, 2005); and *Direct Payments* (LDC Group et al., 2007), and with the international findings reported above. As stated by one UK interviewee, "No one ever gives back Direct Payments" (Laragy, unpublished interviews, 2005).

The findings also show that information, planning and account keeping services are critically important to the successful use of individualised funding, and that very few people can manage without them. In Sweden, only 3 per cent of people with disabilities chose to self-manage when other options were available. The Victorian IFP project demonstrated that even highly competent and motivated families struggled to access the information they needed. Furthermore, they were reluctant to use their individual funding to purchase case management to access information. The results suggest that service designs need to build in information and support services that are readily available, even if costs are involved.

Charging a universal fee for information, support and accounting services is more acceptable to people than paying individually after funds are allocated. However, this could depend on how much is charged as the IFP project showed that one of the incentives for using individualised funding is having access to more funds. An independent study of the agency supporting this project found that nearly 50 per cent of funds was used for agency infrastructure and case management (Summers, 2007). The IFP families had no hesitation in paying 10 per cent of their funds for account keeping services, but they were reluctant to pay extra for case management support. A feature of the Victorian case study agency and Swedish cooperatives was that they charged less than 10 per cent of funds for these services. It seems likely that established disability agencies will struggle to lower their fees to this level, and it will be interesting to see if the new KDSF agency is followed by others competing in a market economy. Concerns that people with an intellectual disability will be disadvantaged in a market economy and become isolated, neglected or abused (Brennan, 2006; Fyson & Kitson, 2007; Gauthier, 2000; Knapp, 2007), have not been realised in these studies.

My findings support other evidence that individualised funding does not necessarily place people with an intellectual disability at greater risk (Social Care Institute for Excellence, 2007). However, it is acknowledged that the small sample sizes and methodologies used may not have uncovered instances of neglect or abuse. The only specific issues raised in my studies were by a Swedish administrator who had concerns about a small number of families where family members were employed and there was no external oversight. The administrator was strongly in favour of individualised funding and policies allowing the employment of family members after caring for her dying son, but she wanted more authority to investigate concern in a small minority of families.

A key factor that appears to mitigate against risk is having a range of people involved in planning and oversight taking into account the vulnerabilities of the person concerned, including the fact that people with an intellectual disability suffer particularly high levels of abuse (Fyson & Kitson, 2007). This approach attempts to balance risks with the right to choice and independence which is a challenge (Green & Sykes, 2007); it is consistent with recommendations from the UK Department of Health (2007) that person-centred planning include all stakeholders involved and that clear lines of accountability are needed to responsible government representative. Furthermore, it is important that the mechanisms used are culturally appropriate.

Cultural differences mean it is not possible to simply transplant policies and procedures without regard to local conditions. While detailed planning is widely acclaimed in the UK and Australia, this is not the case in Sweden where it was often viewed as an intrusion upon an individual's rights. Most Swedes with an intellectual disability attended a day centre and individualised funding is only used to support their lifestyle at other times. Planning under these circumstances is substantially different to the 'whole of life' planning conducted elsewhere. Even in the UK however, detailed person centred planning has its detractors. One interviewee reported it was sometimes imposed upon unwilling recipients in an inflexible and insensitive manner. It is also noted that the expanding *UK in Control* project does not use detailed planning and reviews for risk management and accountability (in Control, 2008).

Victoria uses planning, reviews and detailed accounts to provide oversight to the vulnerable and to account for public funds. The Victorian case study demonstrated a comprehensive approach planning that included the wishes of the person concerned as much as possible. The young man

was not included in meetings because of his severe intellectual disability and autism, but considerable efforts were made to consider his point of view as judged by the diverse group of people attending. This contrasted with the approach taken in the Victorian IFP project where no formal mechanisms were established to include the person with a disability. In the IFP project, parents were supported to attend person centred planning workshops, and by all accounts this resulted in new activities and significantly improved quality of life for their sons and daughters with an intellectual disability. However, there was no active mechanism for including their wishes, and this included a young man with a physical disability who attended university. Each individualised funding project is created within a specific context to meet specific needs, and the flexibility of this approach contributes to the advantages achieved. Just as the UK Department of Health (2007) provided guiding principles to minimise risk, meetings like this Round Table discussion may lead to principles for including the wishes of people with an intellectual disability in all individualised funding projects. These could be used as appropriate within the particular context.

## Conclusions

When considered together, the findings from the different studies make a compelling case for individualised funding providing new opportunities and advantages for people with an intellectual disability. Safeguards for people with an intellectual disability are needed and do mechanisms exist to protect the vulnerable. The involvement of a range of people in planning meetings and reviews, and oversight from agencies employing support workers provide safeguards for those who are vulnerable appear to be effective, but more studies need to be undertaken to identify what factors could escalate risks.

Without any of these mechanisms, individualised funding could present unacceptable risks to vulnerable people, regardless of type the type of disability they have. The principles for managing risk provided by the UK Department of Health (2007) should be considered for all individualised funding projects. They acknowledge that some risk-taking can be appropriate for people to live full and rewarding lives, and they recommend that shared decision-making is the best strategy when making these difficult judgements. Furthermore, principles need to be developed in Australia to promote the voice of people with an intellectual disability in individualised funding projects as there is a danger of them being overlooked.

It needs to be remembered that risks faced by people with an intellectual disability exist on

many levels and they are not restricted to the possibility of exclusion, isolation, neglect or abuse. Not having their voice heard in planning decisions is a threat to their autonomy, and not having adequate resources for disability supports, income, housing and health care is a threat to their well-being. Individualised funding does not necessarily exacerbate these problems and nor is it a panacea. All future studies need to consider the complexity of people's lives when identifying what safeguards are needed for specific groups of people in specific contexts, and to question whether there are adequate resources, regardless of the funding model preferred.

## References

- Askheim, O. P. (2005). Personal assistance—direct payments or alternative public service. Does it matter for the promotion of user control? *Disability & Society*, 20(3), 247–260.
- Bigby, C., Fyffe, C., & Mansell, J. (2006). *Roundtable on Intellectual Disability Policy*. Paper presented at the Roundtable on Intellectual Disability Policy, Institute of Advanced Study, La Trobe University, Bundoora.
- Brennan, D. (2006). Community services: challenges for the 21st century. In A. McClelland & P. Smyth (Eds.), *Social Policy in Australia -- Understanding for Action* (pp. 224-237). South Melbourne: Oxford.
- Commission for Social Care Inspection. (2008). *State of social care in England 2006-07*.
- Department of Health. (2007). *Independence, choice and risk: a guide to best practice in supported decision making*. London.
- Department of Human Services. (2008). *Individual Support Package Guidelines - Draft June: Disability Services*.
- Disability Services Commission. (2003). *Review of the Local Area Coordination Program Western Australia*. Western Australian.
- Fisher, K., & Campbell-McLean, C. (2008). *Attendant Care Direct Funding Pilot Project Evaluation - Final Report*. Sydney: Social Policy Research Centre, University of New South Wales & Disability Studies and Research Institute For the NSW Department of Ageing, Disability and Home Care.
- Forder, J. (2007). *Self-funded social care for older people: an analysis of eligibility, variations and future projections*. London: Commission for Social Care Inspection.
- Fyson, R., & Kitson, D. (2007). Independence or protection - does it have to be a choice? Reflections on the abuse of people with learning disabilities in Cornwall. *Critical Social Policy*, 27(3), 426-436
- Gauthier, P. T., Joseph. (2000, July 2000). *Individualised Funding, Choices in Support for Independent Living (CSIL)*. Paper presented at the The first Internation Conference on Self-Determination & Individualized Funding, Seattle.
- Green, D., & Sykes, D. (2007). Balancing rights, risk and protection of adults. In C. Bigby, C. Fyffe & L. Ozanne (Eds.), *Planning and Support for People with Intellectual Disabilities* (pp. 65-83). Sydney: UNSW Press.
- In Control. (2008). *A Report on in Control's Second Phase: Evaluation and learning 2005-07*: England.
- Individual Budgets Evaluation Network. (2007). *Individual Budgets Evaluation: A Summary of Early Findings*. Kent, England: Personal Social Services Research Unit and consortia of universities. : Personal Social Services Research Unit – Kent; Personal Social Services Research Unit – London School of Economics; Personal Social Services Research Unit –Manchester; Social Care Workforce Research Unit – King's College London; Social Policy Research Unit.
- JAG Sweden (Jämlikhet Assistans Gemenskap). (2006). Equality, Assistance and Community (Jämlikhet, Assistans och Gemenskap): (Unpublished interview, Laragy, September).
- Knapp, M. (2007, October). *Individual Budgets and Beyond* Paper presented at the Independent Living Association Conference, from London School of Economics, West Sussex.
- Laragy, C. (2002). Individualised Funding in Disability Services. *Competing Visions: Refereed Proceedings of the National Social Policy Conference 2001, SPRC Report 1/02, 1, 263-278*.
- Laragy, C. (2004). *Individualised Funding/Family-governed Project: Evaluation of a pilot project conducted by UnitingCare Community Options*.: The University of Melbourne.
- Laragy, C. (2008). 'Outcomes' evaluation 2007 *Individualised Funding Project: A project conducted by UnitingCare Community Options*.: La Trobe University.
- Laragy, C., & Naughtin, G. (2008). *Increasing Consumer Choice in the Aged Care Sector*. Melbourne: Social Policy and Ageing Program Research and Policy Centre, Brotherhood of St Laurence.
- LDC Group, Dimitriadis, L., Laurie, D., Lane, J., & Lyall, M. (2007). *Evaluation of the Direct Payments Project, Final Report: Community & Individual Support, Disability Services, Department of Human Services, Victoria*.
- LIME Management Group. (2005). *Evaluation of Support & Choice Implementation. A report for the Victorian Department of Human Services*. Victoria.

Mansell, J. (2006). Deinstitutionalisation and community living: progress, problems and priorities. *Journal of Intellectual & Developmental Disability*, 31(2), 65-76.

Productivity Commission. (2008). *Trends in Aged Care Services: some implications*. Melbourne: Productivity Commission.

Riddell, S., Priestley, M., Pearson, M., Mercer, G., Barnes, C., Jolly, D., et al. (2006). *Disabled People and Direct Payments: A UK Comparative Study*: ESRC Award RES-000-23-0263.

Sarantakos, S. (2005). *Social Research* (3 ed.). Hampshire: Palgrave MacMillan.

Social Care Institute for Excellence. (2007). *Choice, control and individual budgets: emerging*

*themes*. London, England: Social Care Institute for Excellence. <http://www.scie.org.uk/publications/briefings/files/scare20.pdf>

Summers, M. (2007). *Great Expectations: A Policy Case Study of Four Case Management Programs In One Organisation*. The University of Melbourne, Melbourne.

Ungerson, C., & Yeandle, S. (2007). Conclusion: Dilemmas, Contradictions and Change. In C. Ungerson & S. Yeandle (Eds.), *Cash for Care in Developed Welfare States* (pp. 187-207). Hampshire, England: Palgrave Macmillan.

Victorian Disability Advocacy Network. (2008). *Individualised Funding -- Principles & Implementation Guidelines*. Victorian Disability Advocacy Network.

# INDIVIDUALISED FUNDING IN THE CONTEXT OF SCARCE RESOURCES AND INACCESSIBLE HOUSING MARKETS

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Individualised funding is often promoted as a useful device to increase choice for people with intellectual disabilities, enabling them to 'purchase' services from a less restricted range of options (Bostock et al., 2004; Harrison and Davis, 2001; Wood, 2004). However, the implications of individualised funding may vary, depending very much on the strategies of implementation and the context in which it is delivered. In Victoria, individualised funding schemes have been introduced as part of a broader policy agenda to individualise the disability services system under the Victorian State Disability Plan 2002-2012. Growth funding in disability accommodation and support has been redirected towards individualised funding schemes which provide recipients with a limited number of support hours each week, and are not attached to a specific place of residence. Individualised funding in Victoria is distributed in the context of an under-resourced services sector, shortages in affordable and accessible housing in the private market and a range of other exclusionary practices in the community. This paper thus examines the implications of implementing individualised funding in these circumstances.

The paper is based on findings from a broader research project on the notion of choice in theory, policy and practice in housing and support for people with intellectual disabilities. The project involved interviews with over 50 people from the disability sector in Victoria, including Department of Human Services (DHS) officers, senior managers in non-government support agencies, disability rights advocates, members of parents associations and people with intellectual disabilities. Participants were targeted from various DHS regions. This paper discusses four main themes which have emerged from these interviews related to the provision of individualised funding in Victoria. These are the challenges of:

- balancing individualised funding with spatial planning;
- addressing exclusionary practices in the

community to which people receiving individualised funding are particularly vulnerable;

- determining funding levels to avoid the exclusion of people with high levels of support needs; and,
- setting and maintaining clear standards of housing under individualised funding.

## Individualised Funding and Spatial Planning

Geographic and regional planning research makes several distinctions between people-centred and place-centred policy approaches to distribution of government funding. A place-centred approach targets locations and provides assistance mainly in the form of infrastructure and community facilities. People-centred approaches, in contrast, are targeted at individuals with no consideration of their location and focus on issues of education, taxation and financial assistance for individuals to purchase or rent housing wherever they choose. Two main assumptions underlying people-centred policy approaches are 'that there is no friction in the adjustment process and that people can and will move jobs and residential locations to achieve their personal or family objectives' (Stimson et al., 2003, p. 145).

For people with intellectual disabilities, a people-centred policy approach means increasing emphasis on individualised funding schemes and rent assistance to live in the private housing market. A place-centred approach, on the other hand, means that the government develops housing and support services where they appear to be most needed. Advocates of people-centred approaches argue that these offer more control for service users because they are free to use their funding packages to purchase services of their choice. However, in Victoria, there is simply not enough private-market affordable housing suitable for the housing needs of people with intellectual disabilities, and very often they do not have sufficient credit to purchase the supports they require.

Victoria's affordable housing stocks are shrinking significantly and rapidly in recent years. In March 2007, according to the State Government's Office of Housing figures, 16.8% of new lettings were considered affordable (rent price within 30% of household's income). A year later this rate has fallen to 8.9%. Median rent prices for a one-bedroom unit in Melbourne was estimated in March 2008 at \$235 per week and at \$120 per week in regional Victoria (Department of Human Services, 2008a). This is far from affordable for

most people with intellectual disability who are reliant on their pensions and on rent assistance to finance their housing. The disability pension basic rate for adults over 21 is a fortnightly payment of \$546.80 for a single or \$456.80 each for a couple. In addition, people with disabilities who do not live in government funded housing, nursing homes or hostels may apply for rent assistance up to \$107.20 per fortnight, which is the maximum assistance for a person paying fortnightly rent of \$238.33 and above (Centrelink, 2008, p. 23). These figures suggest that a person with an intellectual disability living in a one-bedroom unit in Melbourne is likely to pay 72% of their very limited income on rent (*see Figure 1 opposite*) – in the rare cases when affordable housing is in fact available and accessible for them. A study conducted by Berry and Hall (2001) has found that despite the rent-assistance program, low-income households in the general population cannot afford to rent average valued houses of any size in almost any suburb of metropolitan Melbourne, forcing people to search for low-rent dwellings in a time when these rapidly disappear

from the market. In other words, individualised funding and rent assistance – both typical people-centred funding schemes – may allow individuals more freedom to choose, but there is very little to choose from in the private housing market that is affordable.

**Figure 1: Housing expenses versus income**

Monthly pension: \$1092	Monthly rent (Melbourne Metro Average):
Rent Assistance: \$214.4	\$940 = 72% of income
Total income: \$1306.4	

Severe shortages, as well as variance between places, are also evident in access to public housing. Public housing is a major source of affordable housing for people with intellectual disabilities who wish to live independently, due to the severe shortage in affordable housing in Victoria. The table below demonstrates disparities in availability of public housing across DHS regions in Victoria, based on analysis of data published by DHS (Department of Human Services, 2008b):

**Table 1: Public housing access by regions**

	Eastern Metro Region	Southern Metro Region	North & West Metro Region	Gippsland	Barwon South West	Grampians	Hume	Loddon Mallee
Public housing units in region	6339	27,619	15,942	4206	5770	3483	4805	5330
Public housing units per 1000 residents in the region	6.52	23.01	11.38	17.52	16.48	16.50	19.22	17.88
People on the waiting list for public housing	4,485	9,706	14,548	920	2,458	874	1,271	1,077
Number of applicants per public housing unit	0.70	0.35	0.91	0.21	0.42	0.25	0.26	0.20

Table 1 demonstrates the significant disparity between places in terms of access to public housing. These figures also demonstrate severe shortages in public housing everywhere in Victoria, and when the waiting lists are as long as they are there is no real access to public housing anywhere.

Spatial disparities are a result of variance in access to private and public housing, as stated above, and also variance in access to individualised support services. The model of staff employment used for individualised supports means that support workers have to travel at their own time and expense to provide supports to individuals living in different locations. Often, support workers

will not be willing to travel a long distance to work only one or two hours of work, which is the amount of supports typically enabled by the very limited individualised funding packages allocated under current policy. Moreover, a person may require supports at different times of the day (for example, an hour at morning and an hour at night) which are difficult to deliver under such a model, particularly for someone living in a remote location.

Thus people living in remote locations have a real difficulty in purchasing supports, even when they have the funding available. Some people will therefore need to relocate in order to receive

supports. Particularly in rural regions, this can mean giving up the informal support network in the local community where one lives, for the sake of formal support and housing available in another location. This not only undermines the principle of social inclusion, but is also inefficient in economic terms<sup>1</sup>.

Disparities between places and shortages everywhere, in terms of access to housing and support, emphasize the need to balance individualised funding with spatial planning. It cannot be assumed that people are always able to 'choose with their feet' and move in search of opportunity – a notion that Jordan (2006) relates to neoliberal philosophies. Spatial disparities – and, again, lack of services and housing everywhere – could not be fixed by individualising access to funding but by creating housing and services where they are most needed, to cater specifically for people with disabilities<sup>2</sup>.

### **Individualised Funding in the Context of Excluding Communities**

Individualised funding is tied to a move away from specialised group housing for people with disabilities, towards generic housing in the private sector to increase independence, choice and community integration. However, this move may also reinforce the vulnerability of people with intellectual disabilities to various forms of exclusion in the private housing market with diminished support to assist in the integration process. While development of new group-homes has often been subjected to various forms of community opposition (Dear et al., 1980), DHS and support agencies in Victoria have developed strategies to deal with and avoid such events. Much effort is put in place to prevent opposition to the establishment of new group homes (Gleeson, 1986). In contrast, individuals moving to live independently in private rental are more vulnerable to rejection and exclusion by the community.

One mechanism of exclusion is the physical inaccessibility of most of the housing stock, which makes it unsuitable for people with complex disabilities. This form of exclusion is perhaps more subtle than overt community opposition, yet far more effective. My study found several examples,

of people with intellectual disability who had funding available to support independent living in the private rental market, yet could not find accessible accommodation. In Victoria, as in the rest of Australia, there is no legislation to ensure that residential housing is built according to accessibility standards for people with disabilities. Here, the absence of legislation that mandates all new housing should be accessible, and the choice of developers not to make it so, undermines the choices of people with disabilities to live in private rental.

Another effective mechanism of exclusion in the private rental market is the requirement for rental history. Real estate agents and landlords often choose not to rent a property to a person without a proven history in the private rental market. They are not required by legislation to account for such choices. Research conducted in Australia has shown that even the very limited stock of affordable housing available, is occupied by higher income households (Yates & Wulff, 2005), which are perhaps preferred by landlords. Forms of exclusion such as this suggest that the provision of individualised funding should be balanced with investment in specialist services, and also be accompanied by increased pro-active support for people with intellectual disabilities to access private rental, as opposed to formal anti-discrimination legislation, which is mostly ineffective (Cooper, 1999, p. 220).

### **Individualised Funding in the Context of Scarce Resources: More Smaller Packages or Fewer but Larger Packages?**

Figures for 2006-07 indicate that the vast majority of individual packages allocated in Victoria - 77% - are smaller than \$10,000 per year for one individual and only 1% of all individualised support packages provided by DHS exceed \$55,000 (Victorian Auditor-General, 2008, p.1). In comparison, supporting an individual living in a group home costs DHS and support agencies over \$70,000 per year<sup>3</sup>. These figures point to a very difficult dilemma faced by decision makers regarding the implementation of individualised funding: should policy strive to allocate individualised packages of smaller size but to a greater number of people, or fewer packages

<sup>1</sup>In the UK context, Mansell (2007) discusses similar 'hidden costs' related to out-of-area placements.

<sup>2</sup>An example for a place-based approach to planning of supported accommodation services is in the aged-care sector in Australia, under the Nursing Homes and Hostels Review (Commonwealth of Australia 1986: 129). There, a population-based benchmark exists with a formula of 100 Commonwealth funded services supplied per one thousand persons aged 70 years or more. The Government routinely obtains geographic population projections from the Australian Bureau of Statistics, and controls the spatial distribution of aged care services by prioritizing statistical areas which fall below the benchmark (Fleming 2002: 156). Should a similar system be adopted in disability services, securities must be put in place to ensure that people are not congregated in order to meet the benchmark.

<sup>3</sup>In the US, for comparison, out of 24 states that have implemented individualised funding schemes (eleven of which as pilot programs), most have placed no caps on the value of an individualised funding package, and in the few states that did, the cap was usually placed at around US\$20-30,000. In addition to allocating larger individualised packages, most states in the US provide a larger number of individualised packages than Victoria. (information obtained in 2006 in: Walker et al., in press)

but larger in size? The data presented above is clear evidence that policy implementation is tending towards the first target, distributing more packages, but smaller.

There are two main arguments to support this approach: First, the more packages distributed, more people will benefit. This argument may be considered as reflecting a utilitarian approach which values the overall utility of any action for as many people as possible; Second, enabling people with low levels of support needs to move out of shared-supported accommodation with individualised packages, will free up vacancies for other people with high levels of support needs to move in. In Victoria, people with low levels of support needs already living in group homes are encouraged to move out with a particular funding scheme has been introduced, often termed 'Exit Targets'. Policy documents suggest that people who moved out of shared supported accommodation have gained most from the individualised funding scheme 'Support and Choice' in its first year (Department of Human Services, 2005, p. 11). However, in 2004-5 only 55% of the people moving out of CRUs have moved into more independent living arrangements (in private rental or public or social housing), while 31% have moved back to live with their family carers and 14% have moved into other forms of accommodation such as SRSs which are more congregated than CRUs and provide a lower living standard (Kihl Larssen, 2006). In this sense, individualised funding does allow freeing up vacancies in shared supported accommodation for people with higher levels of support needs, but it does not guarantee that people with lower levels of support needs moving out of shared supported accommodation will enjoy a more independent life.

Moreover, what this policy implies is a redefinition of the group home model, by limiting its growth and by linking it with a particular group of clients – people with higher levels of support needs who are excluded from individualised funding, and for whom group homes are the only alternative. This process has been identified by Bigby and Fyffe (2007), who argue that it calls for reforms in the shared supported accommodation model in terms of funding, management, organizational skills and transitional arrangements.

Allocation of larger packages – inevitably in smaller numbers – may be justified by the *Difference Principle*, according to which the role of government is to support the least advantaged members of society (Rawls, 1971). In this context, it means prioritizing rather than excluding people with more complex disabilities and higher levels of support needs. Another argument for allocation

of larger individualised funding packages is that these would help support people with challenging behaviours to move out of group homes. In Victoria group homes have become the default option for people with challenging behaviours because there are no alternatives, despite their evident difficulty to share a home with other residents. Allowing people with challenging behaviours to move out of group homes to more individualised settings, with sufficient supports, may solve many of the compatibility problems which undermine quality of life for most residents in shared supported accommodation in Victoria. Group-homes may thus become more liveable homes. In this particular case, it is thus possible to achieve the *Difference Principle* as well as greater overall utility.

A third argument to support larger packages of individualised funding is an acknowledgement of the process described in the following section, by which allocation of small individualised packages runs the risk of enabling the development of new congregated facilities.

### **Flexibility for Whom? Congregated Facilities Developed under Individualised Funding**

Until recent years and for more than a decade non-government support agencies have had very little control over the development of new housing facilities for people with intellectual disabilities, and have only responded to tenders instigated by DHS. In contrast, currently, some of the new facilities developed by support agencies can be seen as a move towards non-government-sector initiative and control over the development of new housing. This has been enabled by the flexibility of individualised funding, and may be seen as a positive outcome in terms of growing community involvement in the provision of housing for people with intellectual disabilities.

However, the flexibility allowed by individualised funding has in some cases led to the development of congregated facilities by non-government organizations, in many ways the opposite outcome to that which is implied by the notion of 'individualisation'. Because individualised support packages in Victoria are too small to enable most people with intellectual disabilities to live independently, people often need to share their funding packages and accommodation with others. The need to share is reinforced by the shortage in affordable housing in Victoria. Several non-government organisations have therefore developed facilities where people with intellectual disabilities may share their supports and their accommodation expenses.

One organization operating in Melbourne, for

example, has initiated a new development of four adjacent houses on a single site, for people with lower levels of support needs with individual funding packages from DHS. Living in the new development would allow them to share their funding packages in a way that benefits all, as provision of support becomes more efficient and housing expenses are cheaper for the residents. The agency has also developed an architectural design that allows the residents more privacy in their own ensuite rooms, to minimise the implications of living in a congregated facility. It is arguable that such a design might mean better living conditions and more privacy compared to traditional group homes, despite the larger number of residents. However, congregation of twenty people with disabilities on one site is at odds with the principle of community inclusion.

Another support agency operating in one of Victoria's large regional towns is developing a similar facility (see Figure 2 on page 38). There will be a mix of residents with individualised funding as well as a group of people moving in from an existing group home. Up to fourteen people will be able to live in this facility, which is located in a major regional town in Victoria. The agency invested 1.6 million dollars on the development which is built on Crown land. For eight people with individualised funding packages, this will be an opportunity to share the household expenses with one other person in an affordable purpose-built unit. For the support agency, it will be much easier to coordinate staffing for these people. For six other people, already living in a CRU, this will be an improvement in the way their household is designed, with more privacy and better and more modern facilities. However, it will still be very much like a CRU.

Critics would argue that such new developments lead to the clustering of people with intellectual disabilities in enclaves which make it harder for them to integrate in the surrounding community. While the Government's explicit policy is to avoid development of houses larger than 6 bedrooms, its individualised funding schemes – when provided in such small rations in the context of an exclusionary private housing market – drive support agencies to develop estates with more than twice as many bedrooms. In this sense, the flexibility of individualised funding is not so much for people with intellectual disabilities as much as for the service providers and the state government.

Advocates of such developments argue that they create new affordable housing in a time when these are most needed, and that these units are just one option among others. In my view, it is true that such developments do answer a very pressing

shortage in housing. The fact that support agencies have been able to attract funding from various sources apart from state funding to create new housing is also encouraging and is a very positive and important outcome of individualised funding. And, indeed, both developments described above have been planned with much sensitivity to the concerns about their congregated nature, with designs that aim to reduce the negative impacts of such scales. However, future developments may not be as careful, particularly in an era of increasing demand due to demographic change and in a service-system characterised by its crisis-driven nature. Therefore, in order to avoid clustering of people with intellectual disabilities in large facilities, some mechanisms should be put in place to ensure certain standards for housing being built by non-government agencies. One way to ensure this is to ensure individualised funding packages allocated are attached to a person-centred plan which is consistent with the principles of community inclusion in the Disability State Plan and the Disability Act. It is also important to acknowledge that there are alternatives such as key-ring developments, where the efficiency involved in proximity between independent living units is maintained to some extent, and the negative implications of congregation are avoided (Poll, 2007). Key-ring developments require that a number of affordable housing units are made available for people with disabilities in a single neighbourhood. Moreover, key-ring models cannot rely solely on individualised funding, and require group-based funding to ensure that even if some of the network's members leave, it does not collapse. Nevertheless, key-ring models target people with low levels of support needs (Simons, 1998), and investment in such models should be accompanied by investment in other models more appropriate for people with more complex disabilities and higher levels of support needs.

## Conclusions

Advocates of individualised funding suggest it is a mechanism to increase choice and control for people with intellectual disabilities. This paper also suggests another important positive benefit of individualised funding, which is an opportunity for community-based organizations to initiate development of new housing and attract funding from sources other than the State. However the outcomes of individualised funding vary, depending on the way allocation is prioritised and on the availability of affordable and accessible housing in the private market. Some biases are inevitable: in Victoria, diverting growth funding from investment in services to individualised funding has had negative implications for people with higher levels of



## References

- Australian Housing and Urban Research Institute (2002). Improving housing and support service co-ordination for people living with mental illness, *AHURI Research & Policy Bulletin* (pp. 1-4). Melbourne: AHURI Australian Housing and Urban Research Institute.
- Berry, M., & Hall, J. (2001). *Policy options for stimulating private sector investment in affordable housing across Australia: stage 1 report, outlining the need for action*. Sydney: Affordable Housing National Research Consortium.
- Bigby, C., & Fyffe, C. (2007). An analysis of the current policies on housing and support for people with intellectual disability and complex or challenging support needs in Victoria. In C. Bigby & C. Fyffe (Eds.), *Second Annual Roundtable on Intellectual Disability Policy* (pp. 18-26). Melbourne: La Trobe University.
- Bostock, L., Gleeson, B., McPherson, A., & Pang, L. (2004). Contested housing landscapes? Deinstitutionalisation, community care and housing policy in Australia. *Australian Journal of Social Issues*, 39 (1), 41-62.
- Centrelink (2008). A guide to Australian Government Payments. Canberra: Australian Government.
- Cooper, M. (1999). The Australian disability rights movement lives. *Disability & Society*, 14 (2), 217-226.
- Dear, M., Taylor, S. M., & Hall, G. B. (1980). External effects of mental health facilities. *Annals of the Association of American Geographers*, 70, 342-52.
- Department of Human Services (2005). Evaluation of Support & Choice: How did the first year work? Melbourne: Victorian State Government.
- (2008a). Rental Report, March Quarter 2008. Melbourne: Victorian State Government.
- (2008b). Total number of applicants on the public housing waiting list as at June 2008, Office of Housing. Melbourne: Victorian State Government.
- Felce, D., Perry, J., Romeo, R., Robertson, J., Meek, A., Emerson, E., & Knapp, M. (2008). Outcomes and costs of community living: semi-independent living and fully staffed group homes. *American Journal on Mental Retardation*, 113 (2), 87-101.
- Fleming, B. (2002). Targeting aged care to people who are financially or socially disadvantaged: policy evaluation study about the social gradient in health of older South Australian. *Competing Visions: Proceedings of the National Social Policy Conference*. (Eds: Eardley, T. & Bradbury, B.). Sydney: Social Policy Research Centre, University of New South Wales. Retrieved on 9 February 2009 from: <http://www.sprc.unsw.edu.au/nspc2001/NSPC%202001Papers/RefereedProceedingsNSPC2001.pdf#page=159>
- Gleeson, B. (1986). *Community attitudes to the provision of neighbourhood based accommodation for the intellectually disabled in Victoria*, Honours thesis, Melbourne: School of Environmental Planning, University of Melbourne.
- Harrison, M., & Davis, C. (2001). *Housing, social policy and difference: disability, ethnicity, gender and housing*. Bristol: The Policy Press.
- Jordan, B. (2006). Public services and the service economy: Individualism and the choice agenda. *Journal of Social Policy*, 35, 143-162.
- Kihl-Larssen, K. (2006). *NACS Conference 2006 presentation*. Retrieved on 9 February 2009 from: [www.nds.org.au/vic/NACS/NACS2006/presentations/Kihl-Larssen.ppt](http://www.nds.org.au/vic/NACS/NACS2006/presentations/Kihl-Larssen.ppt)
- Mansell, J. (2007). Services for people with learning disabilities and challenging behaviours or mental health needs. London: Department of Health.
- Poll, C. (2007). KeyRing Living support networks and neighbourhood networks, In S. Hunter and P. Ritchie, *Co-production and personalisation in social care*, London: Jessica Kingsley.
- Rawls, J. (1971). *A theory of justice*. Cambridge MA, Belknap Press.
- Simons, K. (1998) *Living support networks. An evaluation of the services provided by KeyRing*. Bristol: Joseph Rowntree Foundation.
- Stimson, R., Baum, S., & O'Connor, K. (2003). The social and economic performance of Australia's large regional cities and towns: implications for rural and regional policy. *Australian Geographical Studies*, 41(2), 131-147.
- Victorian Auditor-General (2008). Accommodation for people with a disability. Melbourne: Victorian Government.
- Yates, J., & Wulff, M. (2005). Market provision of affordable rental housing: lessons from recent trends in Australia. *Urban Policy and Research*, 23 (1), 5-19.
- Walker, P., Hewitt, A., Bogenschutz, M., & Hall-Lande, J. (In press). *Policy research brief. Implementation of consumer-directed services for persons with intellectual and developmental disabilities: a national study*. Syracuse University Center on Human Policy.
- Wood, H. (2004). Sustaining disabled people in the community: does supported housing offer a real choice? *Practice*, 16 (3), 185-196.

# THE JOURNEY TOWARDS INCLUSION AND INDIVIDUALISED FUNDING – A CASE STUDY OF SERVICE REFORM

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This paper describes the processes and issues associated with an ongoing journey of reform in *Inclusion Melbourne*, an organisation that provides support to adults with intellectual/developmental disabilities in Melbourne, Victoria. A guiding principle and objective of this reform has been to promote more individualised and person-centred support to service users. One of the technical contributions to this process has been the introduction in 2007 of individualised funding arrangements for service users within the organisation.

## A Snapshot of Inclusion Melbourne

Inclusion Melbourne recently celebrated its 58th Annual General Meeting. The organisation was established in St Michael’s church hall nearly three generations ago as *Gawith Villa (GV)*. GV emerged from the early stages of the parent advocacy movement that occurred throughout Australia and in many parts of the world in the 1940s and 1950s. The non-government disability sector was largely built on partnerships between parents, their local communities, and governments working together to improve the lives of a very isolated and vulnerable group of people. Centres were modelled on schools and provided courses in life skills, literacy and numeracy, creative arts, and leisure and recreation. GV received funding through the *Mental Hygiene Authority* which was established in 1951 and headed by Dr Cunningham Dax, a leader in contemporary reforms in mental health and disability services. Dax worked towards separating disability and mental illness at a time when public perception and service provision commonly confused the two conditions. By the 1960’s, government funding was channelled into a formal service model called Adult Training and Support Services (ATSS). This school-based, congregate model remains the centrepiece of the day service sector in Victoria, although it is under increasing pressure to develop into a more flexible, community-oriented model.

The common form of funding support to these NGOs was “block funding” which was broadly based on the size of the organisation.

In 2008, *Disability Services* within the Victorian Department of Human Services (DHS) funded 167 service providers in Victoria that provided services for 8,100 people with a disability. These programs “tend to be group-based activities” and some organisations have commenced a process of “reorientation”. (Department of Human Services, 2008a, p. 20)

Inclusion Melbourne currently serves 70 people with an intellectual disability from 12 Melbourne municipalities. Fifty two services users are from the Southern Region. All of Inclusion Melbourne’s mediated activity for service users takes place in community locations, however 15% of this activity still occurs in traditional centre-based activities in a local community hall. Of the remaining 85% of community activity, 65% of service users’ time is spent in personalised and individualised activities. The remaining 20% of activity time takes place in accredited educational programs for people with a disability at local community venues.

In terms of levels of support need, the Vermont Support Needs Assessment Scale provides the following profile of service users.

Support level	No. of service users	% of service users
Level 2	3	4.25%
Level (core)	32	45.7%
Level (high)	22	31.4%
Level (very high)	10	14.2%

DHS currently funds people who use day services through a number of processes including:

- Funds attached to the individual which may be part of block funding to a day service provider with the level of funding set according to level of assessed support.
- Individualised funding through an Individual Support Package (ISP) process that supports people either in individual or grouped options through a number of programs including *Futures for Young Adults, Community Options, and Flexible Day Options*.

DHS is in the process of changing program policies and in June and July, 2008, released interim guidelines for ISPs and day services respectively, in two documents of 69 pages in total (Department of Human Services, 2008 b,c).

Of the 70 service users with Inclusion Melbourne, 49 people are block funded, 20 have recently been transferred to ISPs and one person is still defined as a *Cohort 10 Futures For Young Adults service user*.

## **The Path of Reform in a Traditional Service**

In some important respects, the reform of an existing service system is more challenging than starting from a clean slate. From an organisational perspective, reform involved both cultural change based on person-centred values and ethical frameworks, and the development and implementation of strategies focused on technical and operational issues.

In around 1990, the Board of GV decided to move away from the traditional ATSS model and examine and change its service model in order to provide a more individualised and community-based service. Subsequently, there have been two stages of development.

The first stage was called "Outreach" and later, "Individual Service". The organisation's commitment to congregate, staff-driven programs, and reliance on paid staff was challenged. The outcomes included a revised constitution, substantial changes to Board and staff, greater emphasis on relationships between service users and community members, the adoption of adaptations of John O'Brien's Personal Futures Planning (O'Brien, 1987), and increased community-based, off-site, outreach services. The key reforms involved the building of a values-driven and intellectually vigorous culture which focused increasingly on outcomes for service users.

The second, current model is called "Individual Support". This developmental stage has focused on further organisational restructuring, particularly around staff roles, and on further technical development with the incorporation of individualised funding *within* Inclusion Melbourne. DHS funding remains essentially based on service user numbers and categories of support needs.

By 2006, Inclusion Melbourne had reached a watershed. People supported in the community did not want to return to congregate programs and service users with high support needs were too small in number to sustain viable specialised group activities. In November 2005 and October

2006, Inclusion Melbourne made unsuccessful bids to the DHS for assistance to provide additional support to enable a small number of service users with high support needs, most of whom were living in community residential units, to participate in the individual support model. These service users remain in the small centre-based program described above. Inclusion Melbourne is currently exploring the possibility of developing more individualised support for these service users by combining planning processes and the resources of day and residential services through collaborations between a number of service providers and, where appropriate, the families of service users. This proposal challenges the existing silo nature of policy, funding, and program streams.

## **Change Strategies**

A number of strategies have been used during the course of these developments. They provide the broader context for the introduction of individualised funding.

### **1. External consultancy**

Since around 1990, Inclusion Melbourne has used a number of external consultancies from national and international experts to provide external guidance, mentorship, and review as the reform process continued.

### **2. Training**

Regular staff and Board training events, and public events have been provided to support developments. These began with a modified *Model Coherency* workshop in 1991 that aimed systematically to review the organisation's services from the perspective of service users' needs. Inclusion Melbourne has consistently focused on training that addressed both the values and culture of the organisation, and technical issues.

### **3. Person centred planning**

Individualised planning processes provided the cornerstone of support. In the mid-1990s, GV introduced a version of John O'Brien's Personal Futures Planning with the aim of achieving more person-centred and participatory planning processes. Later, the organisation piloted the *McGill Action Planning System* (Vandercook, York, & Forest, 1989) with five service users and then progressively offered other forms of person centred planning. With the introduction of the Disability Services Act, three year plans are largely the responsibility of the Department and the organisations that are offered the resources to act as facilitators.

While Inclusion Melbourne is encouraging service users to plan and notionally proposes an allocation of eight hours for this activity, most people are now struggling to engage in effective planning.

#### **4. Widening the range of community outreach programs**

These include TAFE, neighbourhood houses, clubs, groups, recreation programs, and voluntary or paid work experience. Travel training is provided to enable access to these activities.

#### **5. Voluntary support**

Currently, over 11,000 hours of voluntary support to service users is mediated annually through Inclusion Melbourne's volunteers' program.

#### **6. Community partnerships**

Over 150 agencies outside of Inclusion Melbourne provide forms of activity and support to the organisation's service users.

#### **7. Development of Service Quality Indicators**

These indicators keep track of relative proportions of centre-based activities, and both limited and sustained participation in community activities. One measure of the development of the service model is the proportion of activity carried out by Inclusion Melbourne that is individualised and located in the community. In June 1997, 9% of all activity was described as such. In June 2000, the proportion had increased to 30%, and in June 2005, to 60%. In 2008, 100% of all activities occurred in community settings (however, as described above, 15% of this activity still reflects a traditional service model in a local community hall).

#### **8. Periodic reviews**

An example is a review in 2004 that examined the relationship between planning based on possibilities in the community and outcomes such as relationships and self determination.

#### **9. Changes to organisational resources**

Organisational resources were transformed to be more consistent with the service model. For example, cars replaced buses. Provision of personal transport services by the organisation ceased. In 2006, the organisation decided to end enrolments in the old model and only offer services to people seeking personalised

community supports. In essence it was a "you can have anything you want, but you can't have that" model. More recently, Inclusion Melbourne disposed of all but one of its physical locations.

#### **10. Organisational restructuring**

For example, in 2007, the role of Support Coordinator was established to work with up to 15 service users to enhance personalised activity in the community. Support Coordinators help in locating and accessing appropriate activities, arranging direct support staff, and managing the person's budget.

#### **11. Individualised funding**

In July 2007, Inclusion Melbourne introduced a policy of individualised funding based on the funds provided by DHS either as "block" funding or as ISPs. In effect, this provided a separate budget account for each service user upon which they could draw for services and activities provided by Inclusion Melbourne.

The model is based on three areas of service: a minimum service component covering membership fee and basic services, optional additional services and back-up services.

#### **12. Minimum service component**

A service user has to purchase a membership fee, which is based on the provision of five days of activity a week (or a negotiated pro-rata arrangement) and is to meet costs covering the administration of accounts, access to volunteer networks, transport management, and also the purchase of support coordination calculated at an hourly rate. The amount of support coordination will vary according to an individual's circumstances, but is generally estimated as at least two hours a week.

#### **13. Optional additional services**

In addition to these minimum services, a service user can also obtain optional services such as having Inclusion Melbourne facilitate their support planning, or assist in the recruitment, employment, and costs of direct staff who act as community supports. Although transport management is included in the membership fee, service users may also opt to use Inclusion Melbourne's transport arrangements such as the organisation's vehicles or have Inclusion Melbourne book taxis and manage taxi accounts. Further choices include the payment of activity fees, venue costs, and the cost of materials used in activities. Where a service user is involved in group activity, these costs are apportioned equitably across the group.

## 14. Back-up services

While Inclusion Melbourne is committed to supporting people to live their lives in the community and is in the process of phasing out traditional disability group programs, some people still need time to develop strategies for when they are unable to attend their community activity. In this case, Inclusion Melbourne provides a choice of three kinds of back up: drop-in, which offers a safe place for service users to wait before and after activities; term holiday back up; and an emergency insurance program paid for at a daily rate to cover unexpected contingencies such as a last minute activity cancellation and which provides an alternative to the person having to spend time at home.

This individual funding arrangement provides the opportunity for service users to choose between the alternatives provided, to exercise some control over how their funds are used, and a transparent system regarding costs and expenditures. To achieve this accountability and user control, account reporting and budget reviews are held with service users and their families at least quarterly, and more often if circumstances, needs, and interests change.

### Individualised Funding – Issues in Concept and Implementation

Individualised funding is essentially a complex technical response to the distribution, control, and management of funds. Individualised funding is presumed to provide certain benefits including greater transparency, accountability, and equity, and encouraging greater control and self determination for people with a disability and their families. It takes many forms including:

- direct funding to the individual with a disability and/or family;
- individualised funding that may be “portable”, that is, moved with the individual as he/she moves between options;
- funding provided to a service provider that is “tied” to an individual;
- funding managed by a third party (*fiscal intermediary or, in WA, shared management*);
- discretionary funding whereby funding is tied to a particular purpose such as home modifications or transport; and
- funding tied to program parameters such as family, day, or accommodation support services.

Individualised funding may be closely regulated by complex policy and reflect a primary accountability to the funder. It may also be very flexible in response to the person’s individual needs. For example, when Local Area Coordination (LAC) was established in WA in 1988, a form of discretionary funding allowed relatively small amounts of money to be provided directly to families for a wide range of purposes directly related to the specific needs of that family. This form of funding support continues in WA through the *Flexible Family Support* pool of funds and is separate from the other forms of individualised funding administered through the post school options and Combined Applications Process which is described briefly below.

In the case of Inclusion Melbourne, individualised funding represents an effort on the part of the organisation to distribute funding resources equitably across service users based on the levels of funding received from DHS and linked to the service users’ choices from a range of options. It is essentially the next step in the organisation’s move towards individualised and personalised support services.

The technical response is, of course, only part of the picture. In this section of the paper, we discuss some of the issues associated with the implementation of individualised funding, both in the context of Inclusion Melbourne, and also some issues identified from the development of individualised funding in Western Australia.

#### 1. Transparency and accountability

Individualised funding allows for the distribution of resources to each service user according to the funds that have been allocated. That process *may* be transparent and service providers *may* be held accountable. It also allows for a clearer identification of how funds are distributed between items, for example, between administration and direct services. Funders may also gain greater accountability for how funds are distributed. Greater transparency may also make the gap between needs and resource allocation more obvious.

Inclusion Melbourne has struggled with the implementation of individualised funding because of the costs associated with its administration and the real costs of support. Individualised funding has presented some services users with significant new opportunities and outcomes whilst others who rely on periods of intensive support receive reduced opportunities.

## 2. Equity and needs

Individualised funding does not guarantee that resources will be sufficient to meet needs. It may mean that some of the benefits of block funding, such as the sharing of resources that could result in more equitable *outcomes*, cannot occur. For Inclusion Melbourne, this is a critical issue around addressing the needs of its service users who have high or very high support needs, some of whom remain in grouped options that are not financially viable. At this time, Inclusion Melbourne has reached the limits of its reform process for existing service users within its current resources. New strategies are required to generate additional resources.

About ten years ago, Western Australia introduced the Combined Application Process (CAP) by which families and people with a disability could apply up to four times a year through a transparent process for the funding for three types of services: family support, accommodation support, and alternatives to employment. Successful applicants were provided with individual funding. Two major issues emerged from this process. Inadequate funding meant that some families have applied unsuccessfully over 15 times. In addition, if funding was granted, it may not have adequately reflected need. Second, in order to receive priority for funding, the family stories told to the committee, perhaps over and over again, became horror stories that revealed deeply personal information. The CAP is an attempt to achieve some degree of equity and transparency in the allocation of scarce funds, however it occurs at considerable additional cost to families and people with a disability.

## 3. Self determination and control

Individualised and personalised planning and support is intended to promote self determination and governance over support provision for people with a disability or people who are close to the person such as family and friends. The balance between self determination, flexibility, accountability for the use of public funds, and government control is very difficult to achieve. These factors need to inform close, critical examination of developing government policy around individualised funding. For example, the Interim Guidelines of the Disability Services Individual Support Package (Department of Human Services, 2008c) propose a support system that will be tightly regulated and compartmentalised and will reinforce the role of the non-government sector as essentially an arm of government.

Relevant areas in the Interim Guidelines include the formal appointment of fiscal intermediaries and the regulation of people who facilitate individual planning processes.

Self determination and control suggest the availability of choice, however it is clear that most forms of individualised funding provide limited choices. In WA, the Disability Services Commission recently adopted the *Community Living Plan* which is designed to promote alternatives to traditional ways of providing accommodation support for people with a disability. Small amounts of recurrent funds will be made available that will enable families and people with a disability to explore individualised and personalised options in addressing accommodation support needs. The aim is to encourage informal, flexible alternatives that emerge through person centred planning and are linked to informal development of family and other networks. This represents a strategy to encourage innovation and more choice, however there are obvious constraints on the types of options that are likely to emerge.

## 4. Facilitation

Individualised funding initiatives usually require facilitation at the levels of funding and service delivery and the nature of that facilitation is a critical factor. In WA, the introduction of forms of individualised funding in 1988 was associated with the role of LACs who worked directly with families and people with a disability at the local level. Their role included community development and in the early 1990s, through LAC facilitation, a number of *community living associations* (CLAs) were established. CLAs operated at a local and regional level and essentially turned the individualised funding provided into support services. The CLAs developed services that were relatively individualised and, by and large, they avoided congregate options.

Until recently, LACs provided many of the roles of fiscal intermediaries. In 2006, the Disability Services Commission introduced the *Shared Management Model* by which NGOs were able to register in order to manage funds provided to individuals. An issue in this development has been the transparency that now exists in the proportion of an individual's funding that is apportioned to the manager of those funds. This has alarmed some service users. In addition, the language of "self management" has changed to "shared management" and a drift of control back to traditional agencies is evident. Clearly, the influence and control

of large, well resourced NGOs is an issue if a desired outcome is self determination for people with a disability and their families. The WA model has been reviewed recently.

For Inclusion Melbourne, the role of the Support Coordinators is crucial to the implementation of individualised funding. In a manner similar to the role of the LAC in WA, the Support Coordinators are the vital link between the individual with a disability and other key people such as families in identifying needs, locating supports, and maintaining an oversight of the funds allocated to the individuals they serve. As discussed below, the orientation and training of these facilitators is a critical element of individualised and personalised service responses.

Experience with individualised approaches to planning and funding indicates that a significant proportion of people with a disability and families do not want to take on the full formal human service burden. Again, a sensitive balance is required around issues of self determination and governance so that these important objectives are not subverted.

## 5. Purview

From the beginning of the change process, Inclusion Melbourne has struggled with the question of purview. What is the extent of the organisation's responsibility towards its service users? Current disability policy reflects a reductionist epistemology that segments people with intellectual disability according to the constraints of program silos. Separate policy and funding streams make addressing the service users' needs in a holistic, integrated fashion unlikely. One agency provides the accommodation support and a second, support for occupation. Each agency develops its own "person centred plan" and the debacle that occurred with the bureaucratisation of the individual program plan (IPP) in the 1980s seems to have arisen again. The purview issue for Inclusion Melbourne lies in its role of actively supporting the development of a broad range of valued social roles for service users that do not fit neatly into program silos. The role of the Support Coordinator will continue to be challenging as the needs of service users cross program boundaries. It is very apparent that priority needs to be given to effective collaboration and partnerships across these boundaries. Arguably, the interface between various agencies including levels of government, and within and between relevant government departments and service providers may constitute the biggest single

barrier to the achievement of better lives for people with a disability and their families.

## 6. Staff issues

Over the past few years, Inclusion Melbourne has encouraged a shift in staff profiles and skills from an educational role to a broader role around community development. Additional demands on staff focus on the development of partnerships and collaborations in the community through which opportunities can be created for service users. It has become clearer that the role of the organisation is shifting towards encouraging and supporting communities to support service users. The "right" staff need to be found and retained.

## Conclusion

This paper has described the efforts of a small NGO as it has endeavoured to reform and convert its service model to provide more individualised and personalised services. One of a number of technical processes it is exploring is individualised funding. It is very clear that such a technical process has pros and cons and is simply a fallible means, not an end in itself. The organisation has worked to maintain a vision for its service users for a better life and continues to struggle to ensure the underpinning values and ethics remain strong and continue to provide direction. Inclusion Melbourne has now reached a watershed in its journey in which its advocacy and support for people with high support needs has become of critical importance.

## References

- Department of Human Services (2008a). *Changing Days Progress Report*. Melbourne, Vic.: Disability Services.
- Department of Human Services (2008b). *Day Services Policy June 2008*. Melbourne, Vic.: Disability Services.
- Department of Human Services (2008c). *Interim Guidelines of the Disability Services Individual Support Package*. Melbourne, Vic.: Disability Services.
- O'Brien, J. (1987). A guide to life-style planning. In B. Wilcox & G. T. Bellamy (Eds). *A comprehensive guide to the activities catalogue*, 175-189. Baltimore: Brookes Publishing Co.
- Vandercook, T, York, J., & Forest, M. (1989). The McGill Action Planning System (MAPS): A strategy for building a vision. *Journal of the Association for Persons with Severe Handicaps*, 14(3), 205-215.

# **PROBLEM SOLVING, PEOPLE SKILLS, AND PERSONALISED ARRANGEMENTS. EARLY RESULTS OF RESEARCH INTO INDIVIDUALISED APPROACHES FOR YOUNG ADULTS RECEIVING 'FUTURES' FUNDING AT SCOPE**

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## **Introduction**

Person-centred approaches and person-centred planning are an increasingly important feature of disability services as they seek to become more client directed in line with the Victorian government vision and legislation. There are two central changes implemented by the Victorian government. First, is the shift towards an individual form of funding. This shift from block funding to the disability service provider, which has historically shaped a service provider's arrangements, is likely to significantly impact the way in which service providers support individuals. Individualized funding works in tandem with the second shift; that is, the legislative requirement of individual plans which service providers must complete for each individual. Under this provision, it is likely that providers will be accountable under the Disability Quality Framework (2007) for delivering successful outcomes against individuals' stated goals. While this provides a welcome opportunity for the empowerment of individuals with disability, these twin shifts in the disability sector raise a number of significant issues. Scope, in partnership with Deakin University, has recently commenced a research project which will evaluate the outcomes of, and contributors to, a more individualised person-centred approach within a day service context. This paper outlines this project, addresses some of the tentative findings to date, and raises a number of significant issues for further examination.

## **Individualised Funding in Scope**

Scope is a large disability service provider in Victoria offering a full range of services including residential, therapy, day placement, employment, and community inclusion services and supports. Scope works with people of all ages who experience a wide range of disabilities. In 2005, Scope finalised its 2005-2008 Strategic Plan in which it identified a range of objectives relating to developing "integrated individual planning systems" for people supported by Scope, as well as re-orienting services to provide support for people with individualised funding packages (Scope, 2005:9-10). The Strategic Plan took a proactive approach to an emerging policy context in Victoria that was, at that stage, just commencing to trial individualised funding to small cohorts of people with disabilities. In preparation, Scope sought to build person-centred planning (heavily influenced by the approach of Helen Sanderson and Associates) into its service delivery in a range of service types; to re-orient day and residential services to be more person-centred and individualised in their approaches and to foster community inclusion; and to build new systems to support the delivery and tracking of individualised funding.

Scope is currently involved in delivering individualised funding in a range of ways. Some clients are in receipt of individualised funding packages such as Futures for Young Adults. Other people have been Scope clients who are now receiving individualised funds rather than being funded via block funded programs such as traditional day services. Others are new clients who have selected Scope as the service provider for most or some of their individualised funds. Scope also administers brokerage funds, being the regional service provider of Early Childhood Intervention Service Flexible Packages in the Eastern Region (funding packages that aim to assist families with a range of needs).

## **Background to Participating Scope Service**

The Scope service targeted in this research is a group of young adults in a Melbourne region. This was an early group in Scope to step out of a traditional day service model. The group comprises approximately eleven clients in their twenties and thirties – all of whom have a Person Centred Plan. The group is currently comprised of individuals with a range of intellectual disabilities. All of the group members have the capacity to intentionally communicate. Where there are physical disabilities these are relatively 'minor' and do not appear to impede them to any significant extent as they go about their daily lives.

The group has been in existence since 2003 when DHS supplied Scope with a parcel of money to work with a group of young adults – many of whom displayed behaviours of concern including aggressive outbursts. Initially the group was located at a renovated shop front before moving to a local community centre. With the move to a person centred approach, supported and encouraged by the coordinators involved, the group now spends more of its time engaged in a variety of community activities including circus skills training, gym membership, a range of social activities including Club Wild, training courses, movies and shared holidays. The service rents a space in a community centre as a 'base' as well as conducting a number of activities at a traditional day service site. Increasingly, people are engaged in a range of activities in the community. Some members of the original group remain and have indicated that the number of activities has increased, while the level of purpose and meaning in the group involvement has also significantly increased.

The key funding packages for the individuals in the group are 'Futures for Young Adults' – a funding package based on a Support Needs Assessment (SNA) level<sup>1</sup> and which accounts for the majority of participants. This funding is paid directly to Scope at the start of the financial year and is used to provide support staff, costs of courses, activities etc. The other key funding source is the 'Support and Choice' package. Here, a specific amount of hours are allotted by DHS with the money forwarded to a financial intermediate. DHS sets unit costs at \$30.49 per hour, with a kilometer allowance and petty cash for meals, drinks and other activities. How the provider, in tandem with the client, manages the funds will significantly impact on opportunities available in the individual's life.

The coordinator of the group and the support staff have all undergone person centred training, and staff supporting this group aim to work in a person centred manner. In doing so, they seek to provide flexibility in addressing the desires, needs, and goals of clients. Casual observation by the researchers indicates much progress has been achieved with positive outcomes in working with the clients. People's days consist of a range of activities evolving from people's individual plans. Staff have adopted a more personal approach that seeks to know and understand the individuals and their emotional and material needs. Significant, though, is the question of collecting evidence to validate these observations. To what extent is the service proving a better life for a person and how can it be determined if this is the case? Of

importance is the realization of positive outcomes for individuals while considering the enablers and barriers in achieving, or striving to achieve, positive outcomes.

## Person Centred Approach – The Need for Research

There is a vast array of theoretical material defining the person centred approach and arguing for its benefits to people with disabilities. This ranges from the rigid need for a particular method of person centred planning (PCP) as the key to empowering individuals and identifying their needs and desires for a good life, to the more open approach which views planning as merely a guide to the more significant imperative of *action*. Researchers Eric Emerson and Roger Stancliffe, in their research into planning, state a need for planning and action if PCP is not to become just another fad: 'effective PCP must lead to person-centred *action*' (Emerson and Stancliffe, 2004: 24). Further, Tony Osgood claims that services have failed to learn the lessons of past 'innovations' with the risk that organizations may adopt the language but not the practice of person centred planning: 'If services focus on changing language without changing actions, relationships, finances, functions and structures, person centred planning may go the way of other innovations: lost in a mire of organisational cognitive dissonance, a battleground of professional interests' (Osgood, 2003: 4). Emerson and Stancliffe argue for the importance of applied research into the effectiveness of PCP as 'without such information, the well-intentioned introduction of PCP may founder in too many cases' (Emerson and Stancliffe, 2004: 25).

However, few have undertaken the more challenging task of empirically researching an organisation or group and the individuals undergoing the person centred process. The most significant empirical research to date has been conducted in England - 'The Impact of Person Centred Planning' (Robertson et al, 2005) – in which development work and research with disability organisations was undertaken in four locations. The study conducted by this group in England is the first substantial research project that attempts to evaluate the impact of Person Centred Planning and the contextual and organisational factors that affect it.

To our knowledge there has been no research conducted with regard to the outcomes from person centred approaches and planning within day service settings in Australia. The project is the first of its kind in Victoria to develop a

<sup>1</sup>The research projects aims are discussed later in this paper, but do not include an assessment of the adequacy of funding levels of individualised packages.

rigorous process to gain the views of people with a disability about the impact of and outcomes from person centred approaches. While in theory individualised approaches appear to offer many benefits to people with disabilities, it is important to assess the processes and outcomes, and evaluate enablers and barriers to these.

### **The Project Aims and Methodology**

The research involves approximately eight clients, their families or carers, six support staff, the coordinator, service developer and person-centred planners. The research commenced in June 2008 and continues through to August 2009. The project has been outlined to all individuals within the group who have also been given documentation for themselves and their family/carers. The project has undergone a rigorous ethics application with the Scope Ethics Committee.

The central research questions have been framed around four key research areas which aim to identify:

- The outcomes for the clients in an individualised, person centred day service context,
- The process of the Person Centred Approach (PCA) and the degree to which PCA is undertaken,
- To what extent services are changing as a result of PCA,
- To what extent PCA has led to greater community inclusion and the extent to which this has been an identified goal of clients.

The data collection methods of this project seek to identify the viewpoints of clients and staff through a variety of means including: client stories and reflections; interviews with staff, families and carers; review of existing service data such as 'Learning Logs' developed by support staff about individuals, and minutes from staff meetings recording reflections on 'what's working and not working'. There are, however, no well developed methods for assessing the impacts of person centred approaches for clients, and the changes in staff activity surrounding them. To commence this task, the project researchers have begun developing and trialing a method for client self report around outcomes of their individual plan. A measurement tool, the Individualised Client Plan Review, has been developed. This will supplement person centred planning and provide a means of gathering data within the practice of person centred planning and periodic review of plans. This will enable measurement of outcomes as well as collating enablers and

barriers to success. This is of significance given the government requirement to measure outcomes yet with no method developed to date.

The 'Individualised Client Plan Review' incorporates Person Centred Plans and Essential Lifestyle Plans. For researchers it is important that the tool is a working document that provides the opportunity for the person with a disability, and/or their family or carer, and the service provider to consider the enablers and barriers to success, and the further action that needs to be taken to achieve the person's goals. The document has been designed by researchers to enable the recording of goals – both daily and long term. The document will provide the opportunity for evaluation of qualitative data and quantitative data through the measurement of goal achievement. Identified goals can be coded by researchers to determine the extent to which they have been met based on goal achievement scores calculated by the planner performing a person centred plan review. However, emphasis has been placed on the quality of experiences and what is significant about the goal and outcome to the individual. The researchers were mindful that merely to quantify outcomes against goals leads to a simplistic evaluation based on a 'goal achieved?: yes/no' response which does not capture a richer and meaningful individual experience of life.

### **Ethical and Methodological Issues**

In terms of reflection on research method development, the key question is: does the tool provide the categories by which to record the information required to ensure clients the best possibility of successful outcomes? It is important that the planning tool does not become a bureaucratic requirement that is fulfilled and filed away. Plans must be meaningful to the individual and be a tool that aids in achieving a good life for people. Without careful planning followed by action, the risk is that planning and the recording of information becomes an intrusive activity - that rather than acting as a tool of liberation, a plan becomes an invasive instrument that treats a person as a component of a bureaucratic task to be completed.

In terms of measuring change for the person, the researchers aimed for a method that respected the elements of a person's life they held to be important. In general, the literature shows a tension between focusing only on the goals and aspirations identified by the person as a part of planning (as in methods such as Goal Attainment Scaling etc), or focusing on a set of pre-determined outcome constructs valued by researchers (and service providers) such as community inclusion,

social networks, or choice<sup>2</sup>. In dealing with this, researchers identified a range of issues.

Firstly, the kinds of information being sought (eg number of friends and acquaintances, level of community engagement) was ascribed with values by the research team (service provider and government), which were not necessarily shared by the person whose life we set out to document. Why should a data collection instrument routinely set out to measure these elements if they were not held to be important areas of change for the person? Thinking in this way helped researchers critique approaches to measuring community presence and participation<sup>3</sup>. It is important that analytic criteria does not reflect only the values of the researchers/organisation, but should reflect those embedded in the person's plan about the changes they value in their life.

Secondly, there is an overwhelming emphasis on quantity rather than quality in the measurement of outcomes for people with a disability. Within the Scope context, researchers began to critique the valuing of the frequency of an event (eg how often a person goes to the footy) over the quality of the experience and the identification of the contributors to this (eg the accompanying person/people, the footy atmosphere, having a pie and beer, going to the pub at the end of the game etc). Satisfaction, a frequently used concept in disability research, was felt to be a poor proxy for the description of the affective elements of the experience.

These two issues reflect some of the difficulties in developing a method of data collection around outcomes from a person-centred and individualised service approach. Engaging with a person's self-defined and valued changes in their lives, and the nature of what makes for quality experiences and life events, leads away from an instrumental and pre-determined approach to data collection. This in turn results in a deeper engagement with the person, and those around them, and a conversation about how life is going and what the person values in it. To effectively influence practice, it is likely that these conversations need to occur continuously and not just in an episodic manner.

The design of a data collection instrument that also

captured the experiences of the service provider added other issues. In particular, service providers were interested in understanding the barriers and enablers to outcomes. To do this, researchers drew on other Scope research<sup>4</sup> along with the Sanderson 'What's working/not working' tool (Smull & Sanderson, 2006). Additionally, the research team wanted to explore the level of difficulty of achieving each person's plan. This acknowledged the great diversity among aspirations and actions in plans (some framed as easily achievable and others adopting a longer term approach on larger, sometimes systemic issues). In particular, the research team was keen to document the level of resources required in order to achieve goals or actions identified in plans<sup>5</sup>.

Finally, all of the above issues were dealt with in the context of wanting to build data collection about results of service into the actual practice of service providers. That is, the research team aimed to build on existing practice around person-centred planning, and the reviewing and updating of plans. This involved drawing on tools and practices already in use, such as the 'what's working / not working' tool, or the Sanderson and Associates tool '4+1 questions' (Smull & Sanderson, 2006). Given researchers were unlikely to be present during data collection (unless they were invited by the person whose plan was under review), then the data collection instrument had to be clear, concise and user-friendly for a staff member to use as part of the planning and review process.

However, this kind of documentation and use of information raises issues in itself. Planning and reflections on its impacts are intensely personal activities. Yet with governments now providing individualised funds, requirements of accountability for these funds enters this personal domain. Organisations are required to account for government funds and, via processes of person-centred planning, have access to personal records and information about an individual's life outcomes. This project has sought to embed the documentation of outcomes into the ordinary practice of person-centred planning and review. Yet this potentially exposes individual personal information to the organisation in unforeseen ways. It is not clear, in such processes, what

<sup>2</sup>The UK research on outcomes of person centred planning (Robertson et al, 2005) appeared to cover all of these aspects, collecting data about outcomes of plans as well as against a battery of data collection instruments on a range of outcomes areas (eg physical activity, community-based activity, social networks, contact with family and friends, choice etc).

<sup>3</sup>Concepts explored by O'Brien, 1987.

<sup>4</sup>Scope has developed a data collection instrument, Measurement of Outcomes of Support Services (MOSS), that offers a method for capturing barriers and enablers to outcomes of goals.

<sup>5</sup>To do this, researchers adopted a rating scale that could be applied to each goal or action, and aimed to rate the level of difficulty associated with these or the level of change required in order to enact the goal. Ratings of difficulty/change were based on the extent to which each action was able to be implemented within existing service resources (staffing, scheduling etc) (low level), the extent of required changes of service policy, staffing or resources (moderate level), or the extent of required changes of policy, staffing or resources at a number of agencies / services / organisations (high level).

information is to be understood as private, and what information is seen to be about normal quality improvement record keeping and therefore available to be used in organisational accountability to its management and funders. While the research project exists, research ethics clearly define the boundaries of consent, information access and use. However, these boundaries are not similarly well protected outside a research frame.

## Findings So Far

### How the service is dealing with individualised funding

The service has a sizeable group of participants, eleven of whom regularly attend the group activities. Within this cohort, the coordinator reports that his preferred economic model is 'multiples of four', where one staff member can be rostered to support four individuals in a shared activity. Most clients engage in a mix of activities, including time without support staff, time alone with one staff member (1:1), a range of small group activities (i.e. 4+ people) and time in the larger group with up to eleven clients in attendance.

Funds are managed as both 'pooled' or 're-bundled' funds, where individual client funds are joined with other funds, and as individualised funds, where monthly calculations using an attendance hours cost are made against individual budgets. Clients clearly get 'more for their money' when they engage in group activities as staffing costs are spread across all those participating. Where people would prefer 'one on one' then funding will provide them less support hours which has consequences if this arrangement is required by the person. The key element appears to be the co-ordination of client interests into small groups based on shared interests and actions identified through person-centred planning. It is not clear at this point what size of client cohort makes this mixing and matching possible. In this instance, the service supports 26 individuals with only 11 currently participating in activities of this group. The others engage in paid work, volunteering, leisure activities with friends, study etc., and are 'case managed' by the coordinator with their funds being used to pay for their activities. To staff this range of activities, the service employs ten staff, with some working up to 70 hours per fortnight and others only 12, six days a week, across usual operating hours of 8.30am-8.00pm, with some later exceptions.

One interview with a service coordinator identified potential inequities with the level of service any individualised package will purchase. In one instance, one client had previously been

supported by another service provider. This service provider reportedly did not understand the interests and wishes of the client. As a result, the client displayed a range of behaviours of concern and the provider mandated that two staff must be rostered onto every shift with the client (ie a 2:1 ratio). This represented a substantial cost against the client's funding package further reducing funds available to support other activities. On transfer to Scope, the client's needs and preferences were more clearly identified. The client now chooses to participate in many group activities as well as receive one on one support, and is developing social skills and enjoying the contact with others. There are fewer incidents of concern, and the client enjoys increased available funds with which to purchase a greater number and range of activities. In such cases, the individualised package purchased a substantially different amount of services, depending on the service provider's approach and arguably on the appropriateness or responsiveness of activities and supports.

### Kinds of outcomes – case studies

As the research is in its infancy, any findings are tentative and to be considered as opening up further questions and lines of enquiry, as well as informing practice in terms of what appears to be working and what isn't. Two plans have recently been reviewed providing some initial data to consider.

#### Michael (not his real name)

The review of Michael's plan was conducted by a day service coordinator and the team leader at the CRU in which Michael resides. Both expressed a genuine desire to ensure that Michael was given as much opportunity as possible to engage in the activities that were of interest to him. They also supported and encouraged him to explore new possibilities without dictating to him what he should do. It was also obvious that there was a strong and good natured rapport between Michael, the coordinator and team leader, suggesting a warm and caring relationship.

At every point of the review, Michael was encouraged to voice any thoughts he may have had while the reviewers always sought to ensure that he was comfortable with the process. He was asked often what he was happy with, any concerns he had, and what he would like to do in the future – both short and long term. However, time constraints did not allow a more reflective opportunity for all parties. In particular, Michael's intellectual disability may necessitate a more prolonged discussion on some key issues – or

even a number of shorter discussions – to ensure that his views were clearly represented.

On reviewing Michael’s plan, all previously stated goals had been addressed in some fashion, or had been dropped at his request. The most significant goals appeared to attain to emotional needs – the desire for social activities and the need to connect with others. Michael confirmed this when asked by the researcher at the completion of the review what was most important to him. His desire for a relationship was strong and this was clearly understood by the coordinator and team leader who provide opportunities and support Michael in building his social skills and friendships, while also seeking to work with him on his desire for a more exclusive and intimate relationship. He is currently attending a community-based relationship support group.

Overall there was a clear sense that goals were met with things working well in supporting Michael in his needs and desires. What was lacking was a more nuanced understanding of the various experiences. Could they be altered or improved on in some way? Did he clearly recognise that he had the autonomy and authority to change things or consider other possibilities? More time during the review process may have provided the opportunity to more fully allow Michael to explore his understanding of his experiences and what other possibilities he may like to explore. These considerations are significant but should not overshadow the progress that is being made in Michael’s life – both reviewers remarked on the changes in Michael’s behaviour, his increased social life, his overall well being and happiness, and the personal responsibility he now takes in his day to day needs. Such change is not easily quantified.

### **Sally (not her real name)**

Sally’s review was conducted by a Scope personal planner and was attended by a number of Scope support staff, a day service coordinator, and a member of the group. Sally is an articulate woman with her plan recording her skill at public speaking and her honesty in ‘telling it like it is’. As with Michael, the overall impression from her plan is that her goals have been met or are continually being worked on. With those that are being worked on, there is no indication in the document of level of success or whether a new approach needs to be tried to ensure adequate success.

In terms of outcomes, no goals were neglected and all had been actioned in some way. As with Michael’s plan, the researcher is unable to comment on the original planning process, and the extent to which Sally guided the process and whether all her goals were recorded or

whether certain ones were deemed by the service provider to be unrealistic. What was evident was a significant degree of independence – she no longer lives at home and is happily living in a CRU, while she engages in a number of social activities at her request. As with Michael, social and emotional needs are significant and the desire for an exclusive and intimate relationship is forefront to her desires. This has been recorded and understood by the reviewers who have outlined actions to progress Sally in this direction. As with Michael, the previously recorded ‘what is not working well’, had all been addressed.

Overall, the researchers noted the risk of reducing plans to bureaucratic tools that miss out on the quality of experiences and nuances of a person’s life. Yet this too raises a concern about the level of detail in a document. How much personal detail should be recorded? Perhaps it is this significant concern that explains the lack of personal detail in the plans / reviews.

### **Outcomes: barriers and enablers**

Though the sample is small, and the data collection process is still in trial, a number of barriers and enablers to outcomes have been discussed by staff and by people with a disability. Both case studies to date present very positive outcomes in people’s lives. Without further analysis, it is difficult to determine the contributing factors. However, the relationships in the service and group context here are likely to be significant factors. In both cases, the individuals have been attending the group for more than four years. They are well known by staff and the service coordinator, and there has been little change of personnel in these roles across this time. As a result, individuals have a lengthy and deep relationship with staff, especially the service coordinator for whom they clearly display a strong bond. Similarly, the group has established strong peer friendships between some members. Sally explicitly identified these as an enabler to her outcomes, as she relied on friendship and social support to meet her aspirations.

Over time, the Scope staff have established strong communication links with other service providers and people in the individual’s lives. The service coordinator identified that failure to establish or maintain links will serve as a significant barrier to outcomes. As in Michael’s example, both services in Michael’s life work together to support a commonly understood set of aspirations. One service coordinator discussed the importance of working outside of the service silos (eg day and residential services) to take a seamless and responsive approach to the individual’s plan. Another coordinator felt that a major enabler

to outcomes was the clear identification, within the planning process, of achievable actions, who would follow up on these (i.e. residence, family or 'Futures Service?'), and the timeframe within which this would occur. This was understood as an agreement between members of the planning group to which people were held accountable. This negatively affected outcomes when members failed to communicate about or undertake their agreed tasks (whether this be service providers or family). Clearly, where the person centred plan adopts a 'whole of life' (or single plan) focus then shared responsibility, communication and activity across the people and services involved is essential.

This raises issues about the ongoing appropriateness of narrowly conceptualising service parameters as 'day' or 'residential' services, for example. Though somewhat understated, it was apparent that co-ordinating the range of actions and contexts was a key task for the service coordinator. The coordinator endeavours to 'match' the individual to a range of activities and people/groups, developing a patchwork of unsupported and supported activities in a range of environments. When successful, change in a person's life occurs across a range of contexts (home, support service, social life, community organisations) and becomes the 'norm', so that a new way of operating within participating services is embedded as a habit (ie sleeping in, and a changed medication schedule at the residential unit prior to a night out at Club Wild with the group). However, the integration of services and people relies on the day to day planning and organisation that can easily be upset by unexpected events or barriers (such as the taxi not arriving, absence of staff, cancelled classes/activities etc). This planning and organisation is also time intensive, and the service coordinator has indicated that this too can become a barrier to successful integration of people and services.

Organisational characteristics were also identified as enablers to outcomes. Staff identified that the immediate service environment adopted a flexible and supportive approach, making vehicles available after hours, and supporting 'non-traditional' work hours. Similarly, staff attitudes and values were considered an important enabler. To support this, the coordinator offered direct mentoring to staff and modelling of person-centred work practices. This was felt to be at least as effective as formal training. The prevailing culture appeared to be one that affirmed people functioning independently in community life at all time. Staff recounted examples of clients being responsible for their own money in their own wallet, tickets, ordering of food, obtaining receipts etc, on all group activities, with many clients travelling independently to and from activities, meeting up at the venue of choice.

A significant barrier was the multiplicity of funding types received by an individual and of service providers involved in these, as identified in the following case study:

Eric received Centrelink benefits paid to State Trustees who also manage a small inheritance from a family member. He also receives a Support and Choice Package which was recently topped up with an additional package, following a request to the Department of Human Services. These packages are managed by a brokerage agency. Eric currently lives in a large supported residential facility, managed by a different organisation, that does not meet his needs. He is very unhappy in this accommodation, and Scope staff feel it contributes to his behaviours of concern. His package funds are used to purchase services from Scope and another service provider. Eric's main aspiration is to move into his own home. If his total funds were pooled and treated as a whole, he would financially be able to afford either rent or a mortgage as well as the purchase of some in-home support and other activities. Currently, this appears to be not possible, given funds come from different sources that are managed by different agencies.

As a result, one service coordinator identified the benefits of 'one person, one plan, one fund' and the absence of divided management of funds among service providers.

## Concluding Ideas

One of the significant tensions in the grounded reality of individualised funding and person centred approaches, seems to be the tension between the focus on the individual at the expense of the life of an individual among others and within groups. The focus on individualised planning and funds is attended by notions of independence and can lead to an approach that atomises and disconnects individuals, as well as losing notions of inter-dependence. What appears to be lost is an affirmation of an individual's personhood and self-determination, which occurs in solo Tevents and is also dependent on social engagement and groups of people for it to flourish and grow. The research data to date from this project shows people wanting to spend time in a range of social situations and, importantly, with peers with a disability doing activities together. In the case studies presented here, individuals rely on the social relationships established in these groups to achieve the outcomes of their plans. However, the discourse of 'individualisation' continues to run the risk of over individualising a service approach and developing a service response

which is predicated on one to one staffing and arrangements. As one service coordinator stated, an individualised approach 'does not mean one to one' but is a 'personalised arrangement' which includes a range of responses and most of all a 'matching of interests' among service users and other community members. This raises the issue of where do people meet and be together, and what is the future role of fixed day centres that supply many of these spaces presently.

Individualised approaches or 'personalised arrangements' clearly require a significant amount of administration, problem solving and co-ordination. Behind the scenes is the need for a staffing resource to liaise across service providers and fund holders, and to work on the barriers to identified goals. In many instances the barriers to goals are significant. These can be physical access barriers to community based activities or policy or attitudinal in nature. Where they exist, they often require the paid time of a worker to support the inclusion of the individual in these activities. Without this expenditure, these funds would be spent differently. However, in this project, it appears that there is little funded resource to focus on the removal of these systemic inclusion barriers. This falls largely to the service coordinator to 'problem solve' and develop quick fix solutions on a case by case basis.

Equally, or perhaps more important, is the approach of staff. In the data to date it is apparent that the plan is only one tool of a 'personalised arrangement', but the crux appears to be the ongoing discussion, observation, and day to day planning and actions, that occur in conjunction with the person. In the case studies presented here, it was apparent that there was much more going on than the plan, and that success was dependent on constant talking and the fluid responsiveness of all service providers and supports in the person's life. What changes a person's life is the nature of the people in it (including services), and the empathy and relationships between them.

Establishing individual goals is important as is providing the financial means to resource these. But neither person centred approaches nor individualised funding should mean a focus on individuals at the expense of the groups they engage with. Neither process of service provision will inherently bring about outcomes for people with a disability. Instead these are reliant on overcoming the disabling barriers at all levels - individuals, service providers and community. As the sociologist Zygmunt Bauman writes:

*'We all need to gain control over the conditions under which we struggle with the challenges of life – but for most of us such control can be gained*

*only collectively. If there is to be a community in the world of the individuals, it can only be (and it needs to be) a community woven together from sharing and mutual care; a community of concern and responsibility for the equal right to be human and the equal ability to act on that right' (Bauman, 2001: 149-150).*

## References

- Bauman, Z. (2001). *Community: Seeking Safety in an Insecure World*, Polity Press: Cambridge.
- Brewer, J. & Hunter, A. (2006). *Foundations of Multimethod Research: Synthesizing Styles*, Sage Publications: California.
- Carr, W. & Kemmis, S. (1993). *Becoming critical. Education, Knowledge and Action Research*, Deakin University Press: Victoria.
- Department of Human Services (2006). *Disability Services Act 2006*.
- Emerson, E. and Stancliffe, R.J. (2004). Planning and Action: Comments on Mansell & Beadle-Brown. *Journal of Applied Research in Intellectual Disabilities*, 17, pp.23-26.
- Kinsella, P. (2000). *What are the Barriers in relation to Person Centred Planning*, <http://www.paradigm-uk.org/pdf/Articles/jrfpcp.pdf> (accessed October 14, 2007).
- Mansell, J. and Beadle-Brown, J. (2004). Person-Centred Planning or Person-Centred Action? Policy and Practice in Intellectual Disability Services. *Journal of Applied Research in Intellectual Disabilities*, 17, pp.1-9.
- O'Brien, J. (1987). A guide to life-style planning. Using *The Activities Catalog* to integrate services and natural support systems. In B. Wilcox (ed) *A comprehensive guide to The Activities Catalog*. The Maple Press Company: Pennsylvania.
- Osgood, T. (2003). "Never mind the quality feel the width": Person Centred Planning Implementation & Developmental Disability Services' [http://www.paradigm-uk.org/articles/Never\\_mind\\_the\\_quality\\_feel\\_the\\_width/190/31.aspx](http://www.paradigm-uk.org/articles/Never_mind_the_quality_feel_the_width/190/31.aspx)
- Ritchie, P., Sanderson, H., Kilbane, J. and Routledge M., (2001). 'Staying on Track' in *People, Plans and Practicalities: Achieving Change*, Scottish Human Services Trust: Edinburgh.
- Robertson, J., Emerson, E., Hatton, C. & Elliott, J. (2005), *The Impact of Person Centred Planning*, Institute of Health Research, Lancaster University: UK.
- Sanderson, H and associates (2007). *Person Centred Thinking*, <http://www.helensandersonassociates.co.uk/pdfs/hsadminbookaus.pdf> (accessed Sept 11, 2007)

Sanderson, H. and Williams, R. (n.d). *What are we learning about person centred organisations?* [http://www.helensandersonassociates.co.uk/PDFs/Person%20Centred%20Organisations%20PCorgsfinal\\_col.pdf](http://www.helensandersonassociates.co.uk/PDFs/Person%20Centred%20Organisations%20PCorgsfinal_col.pdf) (accessed October 18, 2007)

Scope (2005). *Strategic Plan 2005 - 2008*. Scope (Vic): Melbourne.

Smull, M. & Sanderson, H. (2006). *Person centred thinking*. The Learning Community: Cheshire, UK.

World Health Organization (WHO) (2001). *International Classification of Functioning, Disability and Health (ICF)*. WHO: Geneva, Switzerland.

# INDIVIDUALISED FUNDING: WHAT DOES THAT MEAN?

*Reinforce Self Advocacy*

*Supported by Patsie Frawley*

## **Reinforce Inc.**

### Vision Statement

Reinforce is a self advocacy organisation for people with an intellectual disability.

Reinforce is here to assist, support and encourage independence for people with an intellectual disability.

Reinforce promotes the rights of people with an intellectual disability to be upheld in the same way as everyone else in the community.

### **Who belongs to Reinforce?**

People who have an intellectual disability. People who are passionate about sticking up for the rights of other people.

People who are interested in talking about:

- People's rights,
- Choice and decision making,
- Diversity and social change

### **We have not had a say about individualised funding...**

- Government has not talked to us – Why?
- We are not in the Victorian Disability Advocacy Network – when we were we did not have a real say – Who is talking for people with an intellectual disability?
- We cannot have a say if we do not know what it is all about – How can new ways of funding support be developed without asking people with an intellectual disability?
- Self advocacy is important – other countries include self advocacy in supporting people who organise their own funding and services – Why doesn't this happen in Victoria?

### **How to make individualised funding work for people with an intellectual disability**

- Talk to people with an intellectual disability to see what they want – Who

is helping people know how to get this support and funding?

- If people cannot say what they want they need someone to advocate for them
- Families are not always the right people to do this, they might have a conflict of interest or be in crisis and feel like they have to say Yes to anything– Other countries use self advocates and circles of support. We would like to be involved
- Some people might still want to use services like CRUs and day services, they need proper funding too – We want to make sure services are better too.

### **Questions we have..**

- Do people with an intellectual disability understand what it is all about?
- Who helps people understand – where is the information and training for people?
- Who protects the rights of people so they don't get ripped off?
- It is big dollars – it is important it is kept safe, used for the things that the person wants and needs and is enough to meet people's needs?
- We need to know more about it so we can help people have a say and maybe get involved in the process with people.

### **What people need to know**

- How to get access to this way of funding.
- What will happen when they say they want to go this way – will they lose other supports and services?
- What their choices are and what their rights are and how they can complain if there is a problem
- Who can help manage the money? People with an intellectual disability need the same opportunities as people with other disabilities
- It has to be fair and equal for all people with a disability.

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# SELF ADMINISTRATION AND DIRECT PAYMENTS? SELF ADVOCACY, CIRCLES, MICROBOARDS AND BROKERS.

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## Introduction

One thing upon which there seems agreement in the UK is the extent to which the introduction of direct payments has been significantly influenced by the lobbying and pressure exerted by 'disabled people'<sup>1</sup> (Barnes and Mercer, 2006). Introduced originally as the Independent Living Fund (ILF) to cover a shortfall in welfare payments left people out of pocket, such payments have transformed into perhaps the strongest thread of UK social policy in *Our Health, Our Care, Our Say*: a new direction for community services,

*In social care, we will increase the take-up of direct payments by introducing new legislation to extend their availability...and will pilot the introduction of individual budgets bringing together income streams from social care, community equipment, Access to Work, Independent Living Funds, Disability Facilities Grant and Supporting People. We will develop a risk management framework to enable people using services to take greater control over decisions about the way they want to live their lives', (Department of Health 2007: p.17)<sup>2</sup>.*

Although there are some individualised funding schemes in Western Australia and some pilot projects have been run in other States it is useful to review some of the key experiences from the UK and elsewhere to inform moves to further implementation in Australia. This paper will take *one* aspect of the UK experience, the involvement of people with disabilities in the direct payments framework, and will examine some of the key issues as they might apply in the Australian context. The mechanism through which control and choice are transferred in the direct payments model requires new forms of organisational arrangement. The relative merits of service

brokerage, microboards and circles of support are mentioned in these contexts.

In line with the arguments made by some social policy analysts it will be suggested that,

*'Overall the overriding message...is the central role played by disabled people in campaigning for direct payments and making direct payments schemes work. Ultimately direct payments are not an end in themselves but simply a means to an end (that is, independent living). For direct payments to be truly successful and to become part of mainstream social services provision, social work policy and practice will need to be consistent with the goals of the Independent Living Movement and be guided by the considerable expertise of disabled people' (Glasby & Littlechild, 2002, p.129).*

By examining some of the dilemmas experienced in the UK it will be shown that brokerage, microboards and circles should not be seen as alternative models for the delivery of direct payments but as existing along a continuum which can be accessed to maximise choice and control. Below a short but no doubt familiar story is related and used as a means of testing ideas and developing implications.

Over the past year I have met Rose on a number of occasions. Rose uses an ATSS and each time we speak she says that she wants to work and would like to do office work. She says she wants to use a computer but has still not been given access to one; she says she can help people; she says she can put things away. Each time my words sound hollow when I ask whether she has talked this over with staff at the ATSS. I know she will never do office work, well at least not if the funding for what she does with her day is decided for her and her place in the world dictated by others.

## UK Direct Payment Policy

Since the introduction of the ILF in 1988 substantial changes have taken in the thinking around the implementation, administration and management of direct payments. Each stage has been influenced by the input of a strong disability lobby. The success of the ILF in promoting independence was already gaining substantial recognition from the independent living movement and, in particular UPIAS<sup>3</sup> backed up by influential empirical studies

<sup>1</sup>The term 'disabled people' is one adopted by the British Council of Disabled People (BCODP) and has its roots in the social model of disability in which people with impairments are disabled by society, its actions and structures. In this point of view the creation of disabling barriers is socially constructed and since it is socially constructed, can be addressed with socially re-constructed solutions (more accessible environments, less stigma and so forth).

<sup>2</sup>See also *Independence, Well Being and Choice: Our View for the Future of Social Care for Adults in England* (2005), the Green Paper (that is consultation paper) on adult social care

<sup>3</sup>UPIAS - Was the Union of the Physically Impaired Against Segregation

of the change in people's experiences (Morris, 1993). The first Independent Living Centres (ILCs) which (now central to much work around direct payments in the UK) began to burgeon at around this time, and the now funded National Centre for Independent Living was set up in 1986 and is now Department of Health funded. One activist recalls that from the earliest days NCIL

*'...assisted numerous authorities with Direct Payments Schemes, help set up Direct Payment Support Groups, run and controlled by disabled people through out the country. It has also set up a Direct Payments Co-ordinators network which brings together all the different schemes around the Country twice a year. This provides a forum for constructive discussion and debate and allows for the interchange of good ideas and models of good practice' (Evans, 2003).*

The success of lobbying was further exemplified in the observation that not only national policy had been affected, but local level policy also. As Glasby and Littlechild, (2002: p.54) point out, the uneven distribution of direct payment take-up amongst 150 local authorities in England (Auld, 1999) in the early days was correlated directly with the level to which the Independent Living Movement was established and engaged in local decision-making and negotiations with local authorities.

The importance of getting people together was not lost in the recently completed evaluation of a direct payment project here in Melbourne.

*'All direct payments users appreciated the opportunity to come together to learn from each other..to provide some orientation or support to new direct payments users...The possibility of an organisation auspiced by a peak consumer body was briefly discussed' (LDG Group, 2007: pxiii).*

As will be argued later, there remains some questions in this model to which seeking to empower claimants is the same as listening to a fully developed disability movement.

In talking to Rose with others it is clear she has ideas about her rights and about what she wants to do. Sadly for Rose there are few independent self advocacy projects to which she might belong and she remains unaware of these and their potential relevance for sharing experiences and developing ideas about how to change the way things are.

However in the UK, the implementation of direct payments into national social care policy in 1998 (Department of Health, 1996; Department of Health, 1998) was not unproblematic. The original legislation and policy empowered only those persons able to *on their own* to 'manage' direct

payments to have access to them. The resultant distribution of direct payments amongst different groups of disabled people indicated that by far the majority of the 1404 receiving such payments in autumn 1998 were people with physical disabilities (Fruin, 2000) leading to claims by the report author for the need for peer support, self-help groups and NGO sector input.

It may not be surprising that the UK Government took this stance given the history of the ILF and people with physical impairments (*sic* disabilities) and the subsequently published list of roles they perceived as necessary for people to manage on their own but which were later identified as being part of the 'support service role' (Department of Health, 2003). These included *inter alia*: Knowing the service providers; setting up the scheme including financial management; drafting adverts, job descriptions and contracts; advertising and interviewing; legal responsibilities of an employer, income tax issues; payroll service; budgeting; and emergency cover.

I am no expert, but in amongst the things required to fully manage a direct payment Rose, like myself, would struggle to operate independently. This must imply some system needs to be available to Rose to help her to manage how her direct payment can support her to accomplish her dream of paid work. Rose would therefore be excluded from a direct payment if she had to manage all aspects of it herself under the 1998 policy.

Once again it took sustained lobbying from People First (a national organisation of people with intellectual disabilities drawn from the self advocacy movement) together with NCIL to change the Government's mind along with research undertaken by people with intellectual disabilities (Gramlich et.al., 2002). The resultant requirement to manage their own budgets in the original policy was replaced in their 2003 Guidance. In its glossary this Guidance defines 'Ability to manage' – 'capacity (with or without support) to arrange a direct payment service to meet an assessed need. The ability to 'direct' is more important the difficulty to manage' (Department of Health, 2003: Glossary).

Disability alliances can be complex but can, if organised well, support Rose to have a voice. Rose can speak up for specific issues she faces as well as those that may be of interest to other groups of people with disabilities. But without either a self advocacy movement or national alliance these varied views cannot be heard.

It can be seen then that not only were people with disabilities important in making a case for direct payments but, over time, disability groups

pursuing interests not catered for by the legislation, were able to make their own case for changes to reflect their interests. Indeed it would be true to say that the movement was, and remains, some way ahead of the Government. Given the rise of the Centres for Independent Living and other funded support groups, a concomitant outcome was that people with disabilities were themselves involved in the sector as leaders. Again, though, this was largely people with physical disabilities. At that stage the key issue that arose for people unable to manage direct payments on their own was how a new configuration might be formulated that would maintain their control and power. Again, there was a significant difference between the policy and the disability lobby at this stage.

The policy guidance in 2003 proposed the following:

*'When discussing DPs with people, local councils will wish, wherever possible, to offer the option for them to be put in touch with support group or local centre for independent living, or a peer support group of people who already manage direct payments'* (Department of Health, 2003:p9).

and

*'Councils might decide that they can provide a support service directly in partnership with the local voluntary organisations, or by some other means. Support provided through voluntary/recipient run organisations has been shown to be particularly effective and valued by participants'* (Department of Health, 2003:p9).

and

*'The experience of existing recipients of direct payments is that they find it easier to seek advice from someone who is independent of the council. People receiving direct payments who have been involved with setting up their local scheme often act as advocates for and mentors of those who follow'*. (Department of Health, 2003:p10).

In 2003, two years after the publication of Valuing People (Department of Health, 2001), (the first national policy for people with intellectual disabilities in England for nearly forty years), the policy stance still did not give significant recognition to the range of new frameworks about which people with intellectual disabilities and their allies were already talking, such as circles of support and Joshua Committees. Part of the reason for this may have been the potentially conflicting legislation around the Mental Capacity Act 2005 which continues to see capacity as inhering to the individual. Whilst the Act recognises the need to extend support for decision-making it does not recognise 'circles of support' and 'distributed

and supported decision-making' as suitable surrogates.

Rose may be able to make decisions for herself. But like many of us she may also want to make sure those who are closest to her know what she wants. If she wishes those people can help her plan what to do to accomplish her dreams and actively support her along the journey. The group might include professionals but it really does not have to do so. By drawing those in who can help Rose might get some experience of office work and then decide if that is what she really wants to do.

The history of the development of direct payments in the UK might reasonably be seen as a triumph of the voice of people with disabilities in establishing the grounds and mechanisms for implementation of both legislation and policy. More importantly people with disabilities have become involved in their own supportive roles often in organisations which are funded and through which they are paid.

At least up until 2003 there was a resistance of some local authorities to implement payments and a perceived need to limit demand. This meant that in some areas direct payments were not well promoted and take-up was low leading to what has been termed a 'postcode lottery', i.e. where there are differences in the services received in different geographical locations. Local restrictions, e.g. *specifying* the range of services which might be bought or having '*preferred providers*', have hampered choice of service and often led back to non-individualised and 'off-the-shelf' packages of care. The demands on the time of care managers in the absence of well funded infrastructure and support have also led to the perception amongst some professionals that the model simply does not work. The likelihood is that, like the early days these issues are more prevalent where no disability movement run by and for people with disabilities operates locally to pressure for change. Finally the issues around how best to manage direct payments and who gives consent and makes decisions are still undergoing discussion. These issues are considered in the section to follow.

## Parallel Lines

For some time pre-dating the emergence of direct payments in the UK models for organising direct payments have been operating elsewhere. Collins and Salisbury (1999) report that after the closure of a large institution in Canada families recognised that choice would not be accomplished through the proposed service framework. They set up a local group to seek to manage their relatives' lives,

Calling this a service brokerage agency, families understood that such agencies must respect the decisions made by individuals and their personal networks while operating independently from both government and direct services. In 1977 a proposal to implement individualised funding and establish the Community Living Society (CLS) as an independent brokerage agency' (Collins and Salisbury, 1999: p. 1).

For Rose the involvement of a service brokerage organisation is a Godsend. She does not have to take responsibility for managing things she finds very complex and difficult. She knows what she wants from her personal assistant and also knows if they are getting on well. For Rose it is control over this and whether she is moving to her goals that really counts. But there is still a gap for Rose because there are still no close friends, family or community to help her to make decisions.

Such brokerage organisations and smaller microboards burgeoned in the following years in Canada largely with government funding and support. At the centre of the microboard is the 'circle of support'. As in its original conception such circles were not professionally led (Mount, 1991) but, rather, made up of people who share the person's life and have a continuing commitment to supporting them in their dreams. However, the microboard goes further.

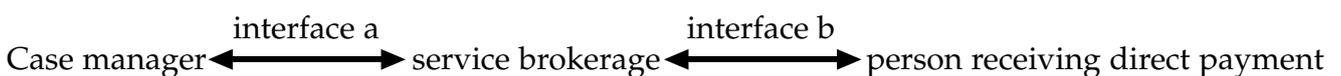
*'A microboard is a small closely connected group of family and friends that forma friendship circle with a person who has a learning difficulty. Microboards also operate as a not-for-profit group. Each microboard is created to support one person...The person for whom the microboard is created drives the direction their board will take. Each microboard is different...microboard members make a commitment to be part of the person's own personal network introducing them to and ensuring they are included in*

*their community. Microboards also contract with appropriate funding agencies to provide individualised funding and service supports... For those people with learning disabilities who may not be able to manage the day-to-day supervision of their services, microboards are a way of remaining at the centre of their control and support but with the additional help they need (Holman & Bewley, 1999,p.66-7).*

A number of points can be made about the microboard model. The first is simply that it may place a significant burden on families, friends and others. Wider arguments suggest that it represents a transfer of responsibility from the State to the individual and that by blurring the boundaries between family care and work it is likely to have most impact on women (Ungerson, 1999). The second is the extent to which it is very much in line with person centred planning, working with dreams and aspirations, with a circle and, additionally, with funding freed to purchase services and support appropriate to achieving these dreams. Again there is evidence that such arrangements within a PCP framework can be hugely if not terminally demanding (Mansell and Beadle-Brown, 2004). The third point relates to the decision-making within the circle itself. There is implicit recognition that the right place to house decision-making for and with a person is amongst those who love and care for the person. Always led by the focus person this group acts to distribute decision-making and to adopt supported-decision-making where necessary. In this model it is the decision-making capacity of the group which is accepted just so long as it remains led by the person themselves.

Over time the nature of service brokerage and microboard models have become significantly more sophisticated along with a clarification of the limitations of their roles and their relationships with case managers and people with disabilities, see Diagram 1.

**Diagram 1: Links between case manager, brokerage organisation and person receiving direct payment**



The brokerage service is a technical service which might take on, with the direction of the person, many of the varied roles required to ensure the payment is successfully administered: Negotiating the individualised funding; technical assistance to develop support plans; Knowing the service providers and 'getting the best deal'; setting up the scheme including financial management; drafting adverts, job descriptions and contracts; advertising and interviewing; legal responsibilities of an employer, income tax issues; payroll service; budgeting; emergency cover; organising evaluation and review.

As the model indicates (interface a) professional case managers or independent/private fee-for-service practitioners cannot act in a brokerage capacity as the potential conflicts of interest mean accountability and control by the person receiving the direct payment are undermined (Dowson, 1990). Although there remain real issues around how the level of funding is worked out (see Duffy, 2005) the case management system must ensure there is no compromise on the flexibility and choice of the client in the use of the resources. However the client choice remains an issue in some cases. For example,

*'Although few local authorities admit to this in public, practitioners and policy-makers at both a local and central level have privately suggested that they overlook the technicalities of ability and consent in situations where they feel that direct payments are the best option for service users', (Glasby & Littlechild, 2002: 68).*

These authors argue the need for support from an independent advocate or microboard or setting up a Trust fund so that in their absence to manage the fund those closets to them can. In control has achieved significant progress in relation to this issue. In their study of self-directed support (Duffy, Waters, Hatton and Lockwood, 2006) the authors found that

*'Professional brokerage played a vital role for some people, but it was not a necessary requirement for most people. In fact where there was the biggest investment in brokerage was also where there was one of the slowest rates of progress' (p.14).*

Additionally there are issues around cost and efficiency. Although many contend that Zarb's original claim that costs reduced by 30 to 40% (Zarb, 1998) was over-optimistic pointing to hidden costs (Dawson, 2000) others suggest that the savings are in the 'creative use of services'. A personal assistant three times a week is cheaper than a block service of a week with the personal assistant 'surplus' to the person's needs at other times. Similarly providing a full brokerage service where the circle can and wish to take on those roles is also an inefficient use of resources.

Most recently this has led In control to argue the case for a 'support broker' to ensure that control is achieved across the direct payment system (interface a and b, Diagram 1). In Control also argue the need for representation and supported decision-making and support planning. The role of the 'support broker' in planning, developing and co-ordinating is a specialist role and would involve developing a decision-making agreement and help for the person in communicating their wishes and desires. The role of support broker would be a significant part of the service brokerage model but a specialist role nonetheless. Indeed the role has other benefits not least tying in the person and their network only to the extent requested or required (interface b).

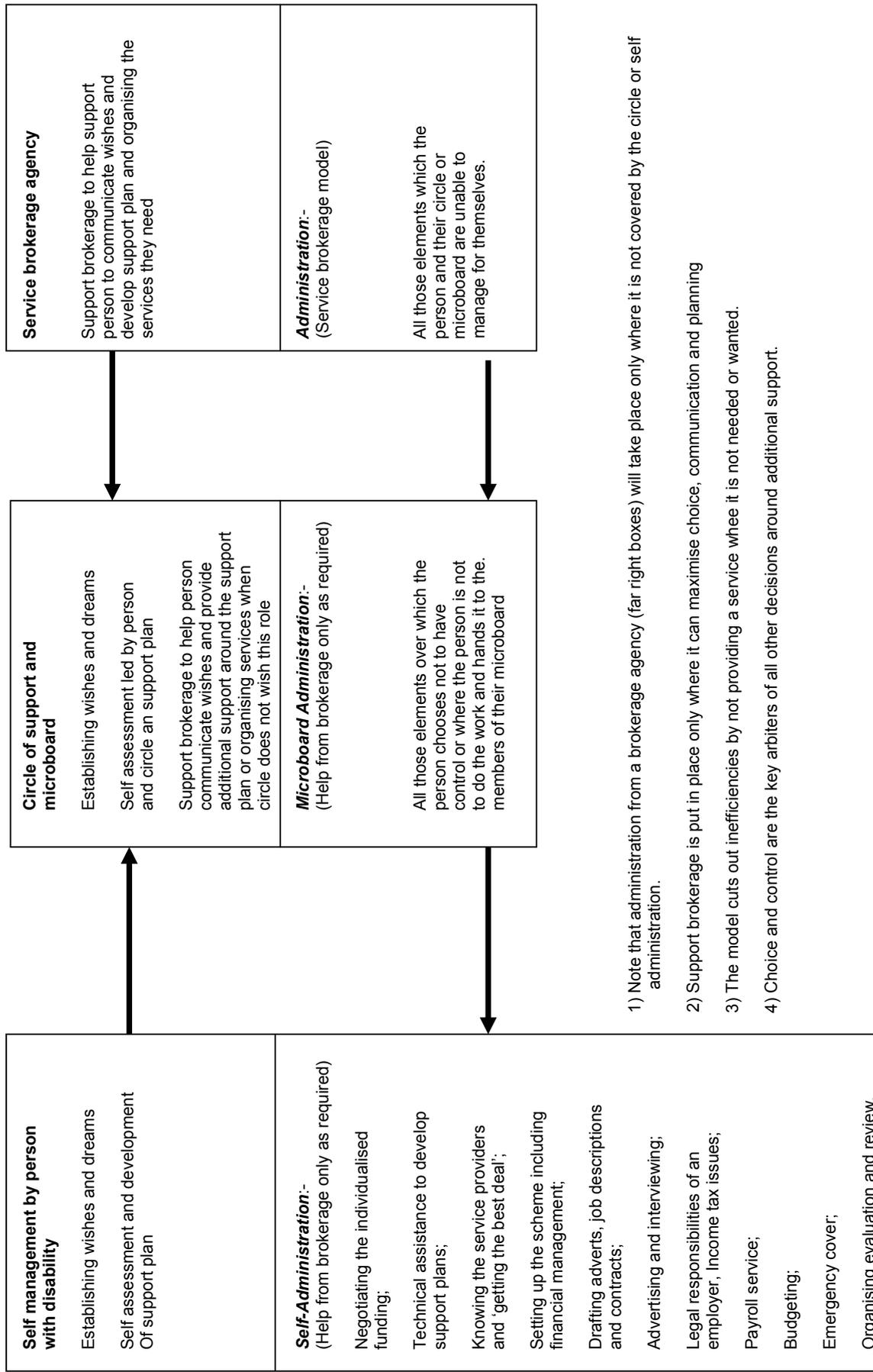
The resultant model based on the rehearsal of ideas outlined above is represented in Diagram 2 which shows a phased move from self management to circles and microboards and only then on to a full service brokerage model. Even in the full service brokerage model the work of a support broker is seen as separate from service brokerage in that it is aimed specifically at establishing the persons wishes, supporting them to communicate and developing a support plan with them. As can be seen the brokerage agency will take on only those parts of the administrative work that the circle or person are unable to themselves manage.

In the absence of a circle of support or microboard Rose now has a support broker who has worked consistently with her around planning her life. Rose had had a spell experiencing a job in both an office and in a canteen. Rose has changed her mind about the work she would like to do and now wants to work in a canteen. She has made a friend at the canteen who has invited her to tea and her mood has really lifted. Rose's personal assistant is looking into whether there are courses Rose can do around catering. For the first time in years she feels like she is doing something that gives her life meaning.

## Some Further Implications

Above it has been seen that people with disabilities, intellectual disabilities included have been at the centre of lobbying for change. They have themselves set up brokerage and support agencies aimed at responding to the views and wishes of people with disabilities and provided valuable expertise on management groups around the implementation and continuing operation of the direct payment sector. They have, too, been substantially involved in research and in developing the expertise around direct payment and practice. An added benefit to these multiple roles has for some been employment. However, based on the model developed, there are further

Diagram 2



ways in which the 'revolution' of direct payments may require change in the service system, drawing further on the expertise of people with disabilities and self advocates.

The traditional model of service provision, of off-the-shelf packages of care that were predictable also meant that centralised decision-making could be undertaken around 'population needs' and around planning services. In addition, since the nature and extent of services were to a significant extent 'predictable in this 'supply-side' model a number of seemingly participatory planning models were possible. For example, the model developed during the All Wales Strategy worked on the assumption that since everyone would have an IPP<sup>4</sup> it would be possible to tell the overall level of need for different services. All needs were collected at local level and local groups fed to County and then national planning groups. In each group representatives of people with disabilities were involved along with family carers and members of the statutory and NGO sectors. Problems in this model included that in no locality did the majority of people have IPPs hence making identification of services problematic; the participation of self advocates was patchy (Whittell & Ramcharan, 1998) and their contributions a 'small voice' (Welsh Office, 1989); the views of family carers often led to calls for more 'traditional' rather than normalised services; and the services available were still under the control of the local authority statutory sector (Felce et al., 1998). The arrangement for local level planning in Partnership Boards under Valuing People (Department of Health, 2001) has similar proposals for participation in decision-making but with additional guidance on the development of services locally. This time the 'engine' of change was person-centred planning and health action planning (Department of Health, 2002a,b).

However, if services are generated via a 'demand' as opposed to a supply-side model then strategic service planning is turned on its head. The statutory sector will no longer be arranging the strategic planning, implementation and monitoring of services. In control further propose a new resource allocation system and a far simplified form of assessment costing significantly less,

*'The mapping of assessment criteria against funding levels has also been less difficult than one might expect. Three independent criteria were proposed:*

- Level of need: expressed as low, medium or high
- Family situation: expressed as whether living in the family home or not

- Complexity: expressed as either yes or no' (from Duffy, 2005:8)

Funding would be applied based on the 12 possible permutations and Duffy claimed that in their study 90% of the assessments were near to present levels of funding based on complex assessment practices.

The language of the statutory sector would, in this model, have to change significantly. In a demand side model there would be some responsibility to identify on a consistent basis the features of services that were found by direct payment users to meet people's needs and wishes; there would be a requirement to continue sourcing community options to seek to build social capital; there would be a responsibility to build capacity where demand outstripped supply and there would be a significant change in the role of disability professionals and disability sector training. To avoid any move back to the "off-the-shelf" and unchanging services it is not conceivable that arrangements such as these can be organised without a significant input from people with disabilities and the disability movement. Indeed some have argued there is a need to undertake this across groups of people with disabilities who see themselves as sharing interests,

*'In order for direct payments to become part of mainstream services, local authorities should develop a strategic approach...to develop direct payments boards or steering groups across all user groups...'* (Glasby & Littlechild, 2002: 68).

This too would represent an important move towards deliberative democracy and to human rights and civil liberties leaving statutory agencies with responsibilities around audit and risk management around the expenditure of public resources.

Rose has with support visited a self advocacy group and is not sure if she wants to go again. She has met some people she liked though. Some people with disabilities have visited Rose to ask her about the people and services have made a difference in her life. They said they would like to send her material on what is happening for people with disabilities and what services are available. Rose's personal assistant has helped her to understand these documents even though they are in easy words and pictures.

This collectivist approach plays a vital role. If direct payments represents the best fit between individualisation, consumerism and markets the danger, as Foucault suggests is that there is a continuation of their Great Imprisonment. From 'round the bend' and hidden away in asylums until they became unacceptable they

<sup>4</sup>Individual Program Plan

will now be disparate and unknown individuals in the community with no collective voice to represent their experiences and lobby for their interests. In this sense the vital necessity of collectivist strategies and action by people with disabilities, to offset the countervailing vagaries and vicissitudes of the liberal market and the pressure to curtail funding at Government level, cannot be underplayed.

## References:

Auld, F. (1999) *Community Care (Direct Payments) Act 1996: Analysis of responses to local authority questionnaire on implementation*. London, Department of Health.

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

Borant, J. (2006) Introduction. In Leece, J. and Bornat, J (eds) *Developments in Direct Payments*. Bristol: The Policy Press.

Carlin, J. & Lenehan, C. (2006) Overcoming the barriers to the take-up of direct payments by parents of disabled children. In Leece, J. and Bornat, J (eds) *Developments in Direct Payments*. Bristol: The Policy Press.

Collins, D. and Salisbury, B (1999) Is Individualized Funding about to come Full Circle in BC? Last retrieve 17th October 2008: <http://members.shaw.ca/bsalisbury/Is%20Individualized%20Funding%20About%20to%20Come%20Full%20Circle%20in%20BC%20-%20revised.doc>

Dawson, C. (2000) *Independent success: Implementing Direct Payments*. York: Joseph Rowntree Foundation.

Department of Health (1996) *Community Care (Direct Payments) Act*. London: HMSO.

Department of Health (2000) *Community Care (Direct Payments) Act: Policy Guidance*. London: Department of Health.

Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21st century*, cm5086. London: Department of Health.

Department of Health (2002a) *Planning with People: Towards person-centred approaches*. London: Department of Health.

Department of Health (2002b) *Action for Health, Health Action Plans and Health Facilitation: Detailed good practice guidance on implementation for learning disability partnership boards*. London: Department of Health.

Department of Health (2003) *Direct payments guidance: community care, services for carers and*

*children's services (direct payments) guidance England 2003*. London: Department of Health.

Department of Health (2005) *Well Being and Choice: Our View for the Future of Social Care for Adults in England*, cm6499. London: Department of Health.

Department of Health (2007) *Our Health, Our Care, Our Say: a new direction for community services*, cm6737. London: Department of Health.

Dowson, S. (1990) *Who Does What? The process of enabling people with learning difficulties to get what they need and want*. London: Values into Action.

Duffy, S. (2005) Transforming the allocation of resources for care, *Journal of Integrated Care*, 13,1, pp1-11.

Duffy, S., Waters, J., Hatton, C. and Lockwood, S. (2006) *Evidence on self-directed support. Submission to ODI of findings on economic sustainability*. Unidentified place: In Control.

Evans, J. (2003) *The Independent Living Movement in the UK*. Last retrieved, 17th Oct, 2008 <http://www.independentliving.org/docs6/evans2003.html#1.3>

Felce, D., Grant, G., Todd, S., Ramcharan, P., Beyer, S., McGrath, M., Perry, J., Shearn, J., Kilsby, M. & Lowe, K. (1998) *Towards a Full Life: Researching policy innovation for people with learning disabilities*. Oxford: Butterworth Heinemann.

Fruin, D. (1998) *Moving into the mainstream: The report of a national inspection of services for adults with learning difficulties*, London: Department of Health.

Glasby, J. & Littlechild, R. (2002) *Social Work and Direct Payments*. Bristol: The Policy Press.

Gramlich, S., Stacey Gramlich, Gordon McBride, Natasha Snelham & Brian Myers, with Val Williams & Ken Simons (2002) *Journey to Independence: What self advocates tell us about direct payments*, Kidderminster: BILD.

Holman, A. & Bewley, C. (2000) *Funding freedom: People with learning difficulties using direct payments*. London: VIA.

LDG Group (2007) *Evaluation of the Direct Payments Project: Final Report*. Melbourne: Community and Individual Support Group, Disability Services, Department of Human Services, August 2007.

Mansell, J. and Beadle-Brown, J. (2004) Person-centred planning or person centred action?: policy and practice in intellectual disability services, *Journal of Applied Research in Intellectual Disabilities*, 17, pp 1-9.

Morris, J. (1993) *Independent Lives: Community Care and Disabled People*. Basingstoke, Macmillan.

Mount, B. (1991) *Dare to Dream: An Analysis of the Conditions Leading to Personal Change for People with Disabilities*. Manchester CT: Communitas.

Ungerson, C. (1999) Personal Assistants and Disabled People: An examination of a Hybrid for of Work and Care, *Work, Employment and Society*, 13, 4, pp583-600.

Welsh Office (1989) *Still a Small Voice: Consumer Involvement in the All Wales Strategy*. Cardiff: Welsh Office.

Whitell, B. & Ramcharan, P. (1998) The All Wales Strategy: self advocacy and participation, *British Journal of Learning Disabilities*, 20, 1: p23-26.

# INCLUSION; ILLUSION OR CONFUSION

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Over the past few decades in many developed countries, *Individualised Funding* packages and practices are commonly provided to support people with disability, including adults with intellectual disability, to live in communities. This suite of practices, which may have many iterations of name or form, generally encompass the common feature that a specific funding package is allocated to an individual for the purposes of individual choice and determinations in regard to resourcing and spending. It is also commonly accepted that if an individual cannot make the full range of choices that may be required, designated assistants or proxy decision-makers may assist the process.

Within the evolution of these practices, it has become apparent that *Individualised Funding* is embedded within a context formed by the meshing and interlacing of particular discourses and principles. For example, linked to the notion of choice are the principles of autonomy, liberty and self-determination along with a concept of empowerment. In turn, imperatives for such choice making may be rights-driven that seek to protect and promote justice. Independence and inclusion are presumed to be intrinsic outcomes of such practices for individuals. With the receipt of specific individualised funding, adults with intellectual disability have the opportunity to become increasingly non-dependent on collective funding mechanisms and to receive person-centred support to facilitate opportunities for increased access to varying domains of community life such as education, employment, citizenship and well being. Hence previous or at-risk experiences of exclusion are seemingly addressed to positively contribute to a concept of 'social inclusion' as promoted by a range of Western governments.

Overwhelmingly, international research evidence suggests that when adults with intellectual disability receive individualized funding packages, they experience a markedly improved quality of life (Stainton & Boyce, 2004) and increased opportunities for social inclusion (Caldwell, 2007; Ontario Roundtable on Individualized Funding, 2000). Importantly, this significance is increased when the responses are targeted to need that is identified from a relational perspective, that is, when the unique particularity of an individual

is respected (Caldwell, 2007). However, despite these findings, the commitment to, and provision of, individualised funding packages from governments for adults with intellectual disability, remains tenuous (Caldwell, 2007). Without intentional policy safeguards as implemented in some jurisdictions, the provision of individualised funding may in the least be threatened, restricted, or perceived as optional (Laragy, 2002); or at worst, be removed from contemporary disability policy agendas (Caldwell, 2007; North Shore Disability Resource Center, 2005). Some common reasons for such actions seem to include differing understandings of disablement; a lack of funding to meet the wide scope of demand on governments; concepts of managerialism; and suspicions of the effectiveness of such practices if autonomy is diminished (DiRita, Parmenter & Stancliffe, 2008; Boyle, 2008). These types of policy interventions risk both that adults with intellectual disability do not experience inclusion; and likewise that their aspirations of inclusion become unattainable because inclusion becomes an illusion.

However, this paper seeks to identify the active conceptual aspects that contribute to such a phenomenon. It will be argued that between inclusion and illusion, there exists much confusion as to how practices encompassing individualized funding are conceptualised. It will also contend that such confusion arises from incoherent moral underpinnings that otherwise would be necessary for individualised funding packages to be less problematic at a social policy level. Therefore in order to undertake such an exploration, this paper will focus on inherent moral and ethical aspects; and in doing so, the resulting impacts of this conceptual confusion for families, systems and communities will be identified and highlighted.

## Ethical Questions

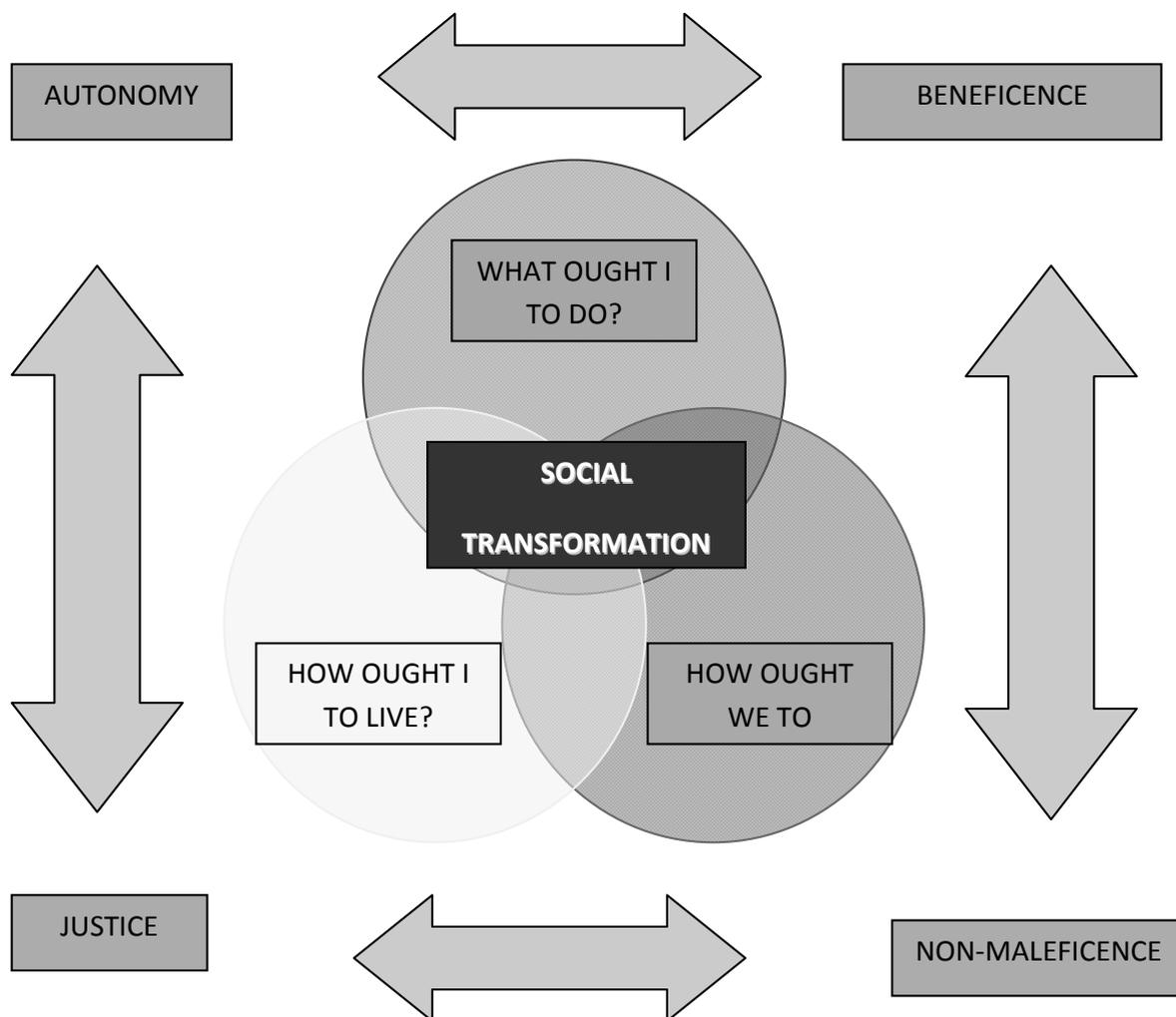
When we undertake an ethical exploration, we must ask a range of ethical questions. Primarily, ethics is about asking and seeking: What is right or wrong? What is good or harmful? What is just or unjust? What rights must be protected? We seek to address such questions in numerous ways. We may apply and privilege various principles such as autonomy, beneficence, non-maleficence and justice. Hence, as individuals, we consider our response to the fundamental ethical questions of 'What ought I to do?' and 'How ought I to live?' In addressing these questions, we may respond from a range of perspectives such as the following (which may include a combination as well): out of a sense of duty (a Kantian or deontological approach); or a sense of utility encompassing the greatest good for the greatest number (a utilitarian approach); or through determinations of fairness

and distributive justice (a social-contractarian approach); or about protecting entitlements (a rights approach); or through various personal attributes such as compassion, honesty, loyalty (a virtues approach).

However, ethics, as well, requires us to think beyond our individualism. The fundamental questions of 'What ought I to do?' and 'How ought I to live?' are enhanced when we extend our concerns in order to have capacity to consider the particularity and contextual features of an issue and a person's or group's specific circumstances. Such an extension then creates a further question of 'How should we respond?' In addressing this question, we also expand our

concerns to the nature and impact of power, history, culture, engagement and relationships, risks of vulnerability, considerations of care, and systems. We then need to concern ourselves with the transformative aspects of considering ethics. Exploring ethics situates us within an active process. It is not merely an intellectual exercise, as we undertake such an exploration because we have a desire to make things better. The very fact that we analyse, then respond or change practices for the better, is testament to a transformatory imperative. The importance of this aspect, therefore, cannot be underestimated. In summary, aspects of applying an ethical exploration to an issue are outlined in Figure 1.

**Figure 1: Aspects of applying an ethical exploration to an issue**



**An applied ethics framework for analysis**

When we consider the issues of *Individualised Funding for adults with intellectual disability* within ethical analyses, it becomes apparent that all of the stated ethical responses could be considered. Therefore, to maximize the capacity to undertake such analyses, this discussion will utilise an applied ethics framework as developed by

Isaacs and Massey (1994). Isaacs and Massey (1994) identify four domains relevant to practical ethics. They name these as the: hermeneutical, appreciative, appraisive and transformatory. The *hermeneutical* domain allows us to be concerned with understanding the contextual features of an aspect, for example, who the stakeholders are, the impact of history and tradition, practice

frameworks, how power and goods are distributed. The *appreciative* domain highlights the significance of self-other relationships, how power impacts in such relationships, how particularity and uniqueness are relevant to ethical considerations; and how collective identity issues also are significant. The *appraisive* domain therefore is the domain of evaluation and analysis; however not from merely an abstract, intellectual

exercise; but rather from informed standpoints that encompass knowledge and insights from the hermeneutical and appreciative domains. Finally, the *transformative* domain outlines a commitment to action by which we seek to make things better in the forms of better understanding, improved practices or social change. The Isaacs and Massey framework is outlined below in Figure 2.

**Figure 2: Summary of the Isaacs and Massey (1994) Applied ethics framework.**

HERMENEUTICAL (Understanding)	APPRECIATIVE (Affirming)
<ul style="list-style-type: none"> <li>• Acknowledging all stakeholders</li> <li>• Focus: Developing frameworks of understanding consonant with the complexity of the ethical situation.</li> <li>• Depends not only on features of the situation; but also on the effects of what “baggage” people bring.</li> <li>• Need to discern the extent of two (2) types of embeddedness:               <ul style="list-style-type: none"> <li>(a) ways in which specific relationships are embedded in roles of power or vulnerability, e.g. status, positions, roles, professionalism, expert knowledge;</li> <li>(b) ways in which a specific situation is itself embedded in broader socio-political, cultural, historical, technological or environmental contexts</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Seeks to promote engagement with others that enables us to relate in ways that acknowledge their richness, complexity, perplexity, and their particularity.</li> <li>• Aim: to enrich and enlarge our appreciation of “their” identity --&gt; involves engaging them, being with them, in a way that recognises and acknowledges their humanity (dignity and human rights etc.)</li> <li>• Involves recognising and acknowledging their particular and “original” way of being human --&gt; their uniqueness, i.e. who they are, not who they are not.</li> <li>• Allows for the recognition of the qualities that they share with others as distinctive group.</li> </ul>
APPRAISIVE (Evaluating)	TRANSFORMATIVE (Commitment to Action)
<ul style="list-style-type: none"> <li>• Aim: to promote the ethical form of life, i.e. to retrieve and resurrect ethical frameworks and standards, and to re-introduce ethical considerations into conversations, decision-making, practice.</li> <li>• Ethical form of life commands an individual and organisational response --&gt;not just individuals, but many organisations are blind to moral issues and quietly and persistently commit “acts of violence” upon their members and outside --&gt; corruption and systemic abuse can occur.</li> <li>• Need to be aware of wickedness and evil played by individuals within organisations, and be prepared to respond.</li> <li>• Highlights the need to appraise (evaluate) our relationships, practices, institutions and communities according to ethical criteria, rather than pragmatic, technocratic or economic criteria.</li> </ul>	<ul style="list-style-type: none"> <li>• Facilitates the response to action, and to ethical and social change.</li> <li>• Decisions will encompass deliberations about responses of a person-specific kind: and/or responses of a structural kind.</li> <li>• Necessitates attention to conditions which limit what is possible --&gt; resources, participant’s attitudes and beliefs, established procedures, power structures, etc.</li> <li>• May be constructive or deconstructive; it is not prescriptive and static, but rather flexible and dynamic.</li> <li>• Not so much an intellectual challenge, but a call to a commitment to action.</li> </ul>

## Applying the Isaacs and Massey (1994) Applied Ethics Framework

### 1. *Hermeneutical*: understanding the contexts of individualized funding for adults with intellectual disability

The evolution of individualised funding for adults with intellectual disability is derived from social, moral, political and economic origins. At different points of history, one, or a combination of these sites of genesis has had profound significance in setting imperatives for individualized funding; and also has influenced how practices have been (a) conceptualized and (b) rationalized.

A significant social influence of Western societies is linked to the deinstitutionalisation movement begun in the late 1960s; and which continued to gain increased momentum through the following decades. Influenced by both the emergence of normalization theories and an active international civil rights movement, pressure was applied to governments around the world for people with intellectual disability to be discharged from large congregate care settings to smaller community care options. Whilst in Australia, early deinstitutionalization practices of the 1960s and 1970s were linked to the provision of block funding to large human service providers, latter practices of the 1980s and 1990s saw an increased application of individualized packages.

This shift also mirrored the shift from disability services based on the medical model to other models where power did not lie solely with professionals (Laragy, 2002).

Contemporaneously, another social influence was the expectation by families that their loved ones would be adequately supported to live within communities. In Vancouver, Canada, the forecasted closure of the Woodlands Institution in the 1970s led a group of concerned parents to propose that, instead of the possibility of dependence for funding on large human service agencies, they instead proposed the provision of individualised funding to become the “framework for the resettlement of Woodlands residents” (North Shore Disability Resource Center, 2005, p. 1). This would have enabled them to control how the needs of their loved ones could be responded to. Although not accepted in this case, this proposed vision was “exported” to other parent groups interested in self-determination around the world, for example in Great Britain, Europe, Australia and the United States (ibid).

Negative relationships with large, professional service providers also provided an impetus for change. Whilst people with intellectual disability may have now been living in communities rather than institutions, individuals and their

advocates became increasingly disenchanted and disempowered by the lack of choice and control in their lives. Therefore, service inflexibility, organisational and professional power, along with a lack of, or restricted decision-making opportunities provided further impetus for change. However, these aspects were also being informed by the increasing moral and political imperatives (Bigby, 2007b), particularly being driven by the independent living and disability rights movements which increased in momentum after the 1975 *United Nations Declaration of Disabled Persons* and the International Year for Disabled Persons in 1981 (Laragy, 2002).

Normalisation and the disability rights movement share the common feature of seeking to redress separation from the mainstream society, and with modifications, became the predominant philosophies of contemporary practices and policies, especially in the promotion of inclusion. The Normalisation movement, though social, is firmly located within an implicit socio-political context and is commonly applied in the area of intellectual disability to redress segregation.

Normalisation seeks equality, but not necessarily power (Clapton, 1999; in press). The disability rights movement, on the other hand, attempts to confront and redress the implicit exclusion within the dominating socio-political ‘structure’, by commanding equity and access of membership through citizenship to the political discourse. Claims of disability rights include seeking equality through power and social justice; and hence liberation from oppression (ibid) by commanding access to a liberal or neo-liberal political context. Theoretical underpinnings of rights-based practices are aligned with social oppression theory, therefore practices encompassing individualised funding indicate the hallmarks of a rights approach; and hence carry specific attributes. The socio-political contexts are redefined from the passivity of welfare dependency to new expected emphases on choice, control, self-determination, freedom, flexibility, individualism and independence. The intention is that individual needs can be responded to more adequately when funding is allocated as close as possible to an individual (Bigby, 2007a; Laragy, 2002; Ontario Roundtable on Individualized Funding, 2000). As Bigby (2007 b) highlights, there is a fundamental shift of power from the supply side (assessed according to category) to the demand side (expressed by individuals). This socio-political shift is also supported ethically whereby rights, justice and liberation, along with the privileging of autonomy, provide the moral imperatives (Cumella, 2008; Reinders, 2008; Pearson, 2000; Clapton, 1999, in press).

To maximise the positive outcomes of individualised funding, various technologies are implemented such as individualised or person-centred plans and direct payments; as well as mechanisms including the use of “service brokers, personal agents, fiscal intermediaries and vouchering mechanisms.” (Laragy, 2002, p. 264) Pearson (2000) identifies how the emergence of direct payments allows greater choice in the provision of services; better satisfaction with the employment of personal assistants; and increased control. Similarly, Stainton and Boyce (2004) state that direct payments (DP) give greater control and independence to the individual receiving the services; and further describe that other beneficial outcomes include “improved self esteem”, “deeper and more lasting relationships, and new interpersonal, vocational and lifestyle opportunities, as a result of the greater flexibility and freedom of choice enabled by DP”. (p. 443)

However, as practices of individualised funding are embedded within a liberal or neo-liberal context, they are also intrinsically linked to consumerism and market forces as people with intellectual disability or their assistant decision-makers (eg families, guardians) manage budgets as devolved to them by funding authorities (Cumella, 2008). Consumer choice and control are enhanced by increasing people’s power to buy the services they want (Reinders, 2008). Pearson (2000, p. 464) observes, “ This [market discourse] focuses on the rhetoric of individual ‘choice’, ‘flexibility’ and ‘control’ in service provision, but is matched with an equal emphasis on ‘cost efficiency’ and ‘service accountability’.” Such a shift also has implications in as much as it is supplemented by a transfer of responsibility and risk from governments to individuals (Bigby, 2007a, 2007b). Hence, as Cumella (2008, p. 179) comments, “[T]he rise of consumerism has been accompanied by a radical reformulation of the role of public services, usually designated as “new public management” (NPM).”

Given all of these factors in regard to understanding the practices of individualized funding, it is not surprising that the context is inherently complex, and not without concerns and critique. As power, rights, justice, material goods, freedom, social support and inclusion are translated and transacted across various historical and contemporary domains, particular issues arise beyond the before mentioned benefits. These are identified by various researchers, and include: issues of service viability (Laragy, 2002); poor uptake of the rights agenda due to ignorance (Laragy, 2002) or inaccessibility (DiRita et al, 2008); poor communication and quality of information (Finlay et al, 2008; Laragy, 2002); limitations or restrictions of choice (Cumella,

2008, DiRita et al 2008); capacity or training, education or skilling of people with intellectual disability or their families to ‘manage’ processes (Swenson, 2008); inadequate skilling of workers (Reinders, 2008); slow pace of change (Laragy, 2002); and discerning which voices constitute the authentic voice for choice-making (Hutchison, Arai, Pedlar, Lord & Yuen, 2007).

Researchers also identify particular concerns especially in regard to the embeddedness of individualised funding practices in neo-liberalism and the controlling mechanism of new public management (NPM). These concerns include: a disruption to the practice of professional human services values, the fostering of contested professionalism, and the engendering of professional mistrust (Reindeers, 2008); an abdication or change of responsibilities by governments (Camilla, 2008, Laragy, 2002); or alternatively, an over-emphasis on the benchmarking, auditing and measurement of outcomes, performance quality, accountability and compliance (Camilla, 2008; Diorite et al, 2008; Reindeers, 2008) and the burden of administration (Bigby, 2007 b); a perceived risk that a logic of management applied by funders in direct support systems may overshadow the importance of the logic of relationships (Bunting, 2008); and a concern about the adequacy, control and distribution of resources along with systems incompatibility (Bigby, 2007a, 2007 b).

However, another significant contextual feature which adds complexity is the nature of self-other relationships and how particular identities are affirmed or appreciated. It is to this domain that this discussion turns.

## **2. Appreciative: affirming and appreciating identities and the nature of self-other relationships.**

A quest of the disability rights movement includes shifting the socio-political identities of people with disability from being perceived as *objects* of the medical discourse, to *subjects* of the political discourse, that is, from those, with needs to be controlled, to those with rights to be provided and protected (Clapton, 2008). Within the liberal state, there is a movement of liberation from welfare recipients to a citizen; and hence is also indicative of the shift from exclusion to belonging. This is affirmed in the Preamble of the *Convention of the Rights of Persons with Disabilities* (2006) whereby states are called to recognize:

*... the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and*

*fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty. (p. 2)*

Inclusion, as the prerequisite for citizenship in a society, is a moral imperative of the disability rights movement (Clapton, in press, 1999). However, Camilla comments that concepts of citizenship can be challenging for people with intellectual disability:

*Public policy for people with an intellectual disability has always confronted the most fundamental of political questions: the qualifications for citizenship (specifically, whether those deemed to be of impaired rationality can be citizens), and the extent to which even the most stigmatized groups in society can be considered worthy of determining their own way of life. As a result, public policies for people with intellectual disabilities (and hence, the way in which people with intellectual disabilities are depicted) have been shaped by the dominant political ideologies of the day. (2008, p. 178)*

As stated, individualised funding practices, with a focus on flexibility, choice, control, self-determination and independence, are closely aligned with a particular political ideology. Not only are they linked to notions of rights, citizenship and inclusion, they also encompass identities predominantly associated within a market context. These may include identities such as consumer, provider, purchaser, funder, and employer that are either attributed to adults with intellectual disability or their assisting families. Implicit within these identities is the sense of empowerment, as the currency of power is also necessarily renegotiated (Laragy, 2002). Various commentators state that significant positive change in well being particularly occurs when the 'unique' needs of adults receiving individualized funding are recognized and responded to within a strong relational context. This may be with their family members; but also when service responses utilize the knowledge, including cultural knowledge, gleaned from relationships (Bunted, 2008; Clapton, 2008; Wilson, Clegg & Hardy, 2008). A service model that is identified by commentators as being appropriate and highly valued is Local Area Coordination, which has been particularly effective in Western Australia (Ontario Roundtable on Individualized Funding, 2000).

Whilst such changes are desirable and thus perceived as significantly positive, there is some evidence though that not all adults with neither intellectual disability nor their families may enjoy

this new status. For some, they may not know of the possibility of asserting such rights; or for others, they would prefer 'to choose' not to have added responsibilities (Caldwell, 2007; Laragy 2002). However, for many others, it may be the nature of contemporary social policies and practices that, at the strategic level appear facilitative of the consumer identity; but at the operational or experiential levels, serve to constrict or minimize the perceived or forecasted benefits. As the Ontario Roundtable on Individualized Funding (2000, p. 7) commented, "The reality is that people with disabilities are often limited in their capacity for citizenship because disability supports are inadequate, inappropriate or unavailable." Whilst constriction may be recognized, it can also be asserted that confusion emerges when, within these situations, other shifts occur which can be attributed to other changed identities, namely that of government and of professionals.

The consumerist agenda, embedded within a market context, is ideologically placed with neo-liberalism. Recent decades have thus seen the introduction of neo-liberal managerially in human services, as in other 'industries'. Camilla (2008, p. 179) outlines the impact of such an example in the form of New Public Management (NPM), which operates in England, and has been "popularized by an Operation for Economic Co-operation and Development report (OECD, 1995), which observed common trends in public management across several countries, particularly in the UK and USA." He identifies the common elements as being that large, inflexible, hierarchical agencies that deliver universal services should be critiqued to deliver more flexible, differentiated services; that opportunity for consumer choice amongst a wide range of providers is paramount; and that the core task of government is then market management and contractual oversight (ibid). However, he argues that such changes may not necessarily enhance the lives of adults with intellectual disability because choice is severely compromised in the absence of adequate options leading in fact to 'illusory choice'; that participatory decision making with government is often just tokenistic and non-accommodating of facilitating needs; and that expressed needs can be reduced to being seen as insignificant or unimportant.

Similarly, Reindeers (2008) analyses the impact on NPM across a range of Western cultures, but his focus is on the role of professionals. He claims that the logic of NPM as purely managerial, elicits the message "values for money: results, not rules." (2008, p. 566); and identifies the main features of NPM as having market and quasi-market mechanisms; promoting decentralization; quality control and consumer responsiveness. With other features such as measuring and monitoring of

explicit standards of performance, disaggregating public bureaucracies into agencies operating with a user-pay system, and overseeing the disciplined use of resources and an emphasis of cost efficiencies, roles of professionals have changed to be dominated by administration, documentation and policing compliance (Reindeers, 2008). For many professionals, therefore, the combination of the implications of the shifts in power and knowledge to individuals and families, coupled with different expectations and roles within managerially, has resulted in a lacuna in which many professionals are left uncertain of their intrinsic roles in practices and whereby the purpose or *tells* of their roles is increasingly blurred (Clegg, 2008; Reindeers, 2008, Diorite et al, 2008).

Another component that is relevant to this discussion, but receives scant attention in research, is that of communities. It is not clear how communities respond, or are cognizant of, these dynamics as mentioned above. It seems that if adults with intellectual disability are positively experiencing inclusion, rather than simple participation, they then are positively engaged with their community through such arenas as friendships, education, employment, citizenship and leisure (Clapton 1999, in press). When engagement is facilitated by practices through relational knowledge such as Local Area Coordination, community relationships are enhanced. In these contexts, the notion of social capital, as discussed by Chenoweth and Stehlik (2004) is significant. However for many other adults with intellectual disability and their families, including those receiving individualized funding, relationships with their community remain restricted, and the triangular dynamic of adult /family, practices and government dominates.

In summary, the changing roles of adults with disabilities, families, government, professionals and communities within an individualized, consumerist and managerially contemporary context can, for some, result in the positive results as previously stated; however the intersections of these roles can create illusion and confusion for many others. An ethical analysis may reveal deeper sources of such concern.

### **3. *Applausive*: evaluating the ethical concerns**

As stated by Isaacs and Massey (1994) the aim of the *applausive* domain is to promote the ethical form of life, that is, to retrieve and resurrect ethical frameworks and standards, and to re-introduce ethical considerations into conversations, decision-making, and practices. As previously outlined, we

can undertake an ethical exploration by asking the fundamental questions of ‘what ought I to do?’; ‘How ought I to live?’ and ‘How should we respond?’ In addressing these questions, we are mindful of ethical principles such as autonomy, beneficence, non-maleficence and justice; and are aware that different ethical theories and perspectives may frame our deliberations.

For governments and practitioners, a core ethical concern across centuries, considerate of beneficence and non –maleficence has been ‘What constitutes a good life?’ Unfortunately, for many people with intellectual disability, the responses to this key question are linked to conceptual and theoretical constructions of ‘good’ as most likely determined by others, and which have had varying and often harmful and damaging outcomes for experiences of inclusion. These encompass profound exclusion through such practices as institutionalization and prenatal testing; technical inclusion through charitable care, assessments and treatments; or legislative inclusion through normalization, rights, justice, and citizenship and quality frameworks. In all of these representations, supporting ethical frameworks have either profoundly betrayed people with intellectual disability if the ‘good’ has been paternalistically determined by powerful others; or due to political constrictions, may have offered only weak support to the fulfillment of a good life as determined by the person themselves or maybe their families (Clapton, 1999, in press). However, it seems that in order to consider the aspiration of ethical inclusion, we are led beyond constructions of the ‘good’ to deliberate and act upon ‘What constitutes a just and decent life?’

From the discussion thus far, it would appear that the ethical currency of individualized funding for individual adults with intellectual disability, with foci on justice, rights, choice, self-determination and empowerment, should be located within this ethical context. Certainly, the positive outcomes as indicated, seemingly contribute to the enhancement of a just and decent life; but what elements within these considerations may be leading to illusion or confusion, rather than inclusion? To address this emerging question, this ethical exploration will focus on two specific aspects: (a) autonomy, ‘person’ and ‘individual’ and (b) the implicit social contract.

#### **(a) *Autonomy*, ‘person’ and ‘individual’**

Individualised funding for adults with intellectual disability is fueled by a fundamental respect of the autonomy of individuals which enables them to be free choosing, self-determining moral agents.

The principle of ‘autonomy’ literally means ‘self governing’. However, in moral terms, to be an

autonomous moral agent, is not merely being able to make free choices, but rather to be able to make free choices with the knowledge of the implications of those choices on the self and others, and recognizing if such choices may be harmful to oneself or another. Therefore, autonomy is a complicated principle dependent upon a capacity for rationality and to reason for its realization. If people are cognitively impaired and their capacity for autonomous decision making is compromised, a designated proxy decision maker such as a family member or guardian may be appointed. Arguably, however, understanding about autonomy in the context of intellectual disability is not simple, but rather significantly complex.

Boyle (2008) outlines how autonomy has been of interest to disability studies over the past few decades. Typically, the focus, whilst linked to concepts of independent living and quests for equality, also has been to critique community care practices (such as in Britain) for their tendency to have people with disability in passive, dependent roles (Boyle, 2008). However, particularly relevant to this discussion are Boyle's differentiations between different understandings of autonomy especially when impacted by cognitive impairment such as intellectual disability. The key points can be summarized as:

- Having a cognitive disability does not mean that persons with intellectual disability are incapable of exercising any autonomy;
- Autonomy may be constricted if such people have a minimum level of rationality;
- That 'extant' capacity for autonomy (that is, a limited, but existing capacity) can still be exercised according to capacity; however 'effective deliberation' will be constrained if people with cognitive impairment are unable to understand the implications of choices or decisions; though it is important that extant capacity for autonomy is exercised in order to contribute to emotional well being ;
- Many people with disability may have sound capacity for decisional autonomy (that is to make personal decisions) but need assistance in the execution of autonomy (that is to carry out their wishes). (Boyle, 2008, pp. 302-303.)

Boyle's paper raises some important considerations that are worthy of further explorations. For example: What is the relationship between autonomy, independence and dependence for

adults with intellectual disability? To what extent are adults with intellectual disability constrained only to the exercise of extant autonomy, rather than decisional autonomy? What are the implications of being cast as minimally autonomous in a moral context? It is in addressing this third question that implications for the other two questions are revealed.

In Western moral tradition, people with intellectual disability are consistently excluded from moral agency on the basis that their cognitive impairment determines incapacity to be fully rational, independent beings; and thus, based on a perception of incompetency, renders their capacity for decisional autonomy improbable (Clapton, 1999, in press). However, this moral exclusion has deeper consequences in that these beings are also denied 'personhood' within such a tradition; and thus become disqualified from moral protection. Not seen as moral person's means that adults with intellectual disability have historically been denied many aspects such as agency, opportunities for independence, and being choice makers and self-determining. The most profound expressions of such denial has, for many, placed them in vulnerable, dependency positions by which they are perceived as always needing alternative decision-makers or that they are judged as having lives not worth living (ibid).

Practices of individualised funding, through claims to human rights and justice, have sought to redress this profound moral exclusion by providing the means by which 'persons' with intellectual disability can have just and decent lives; however it is the mechanisms employed to achieve this that may remain problematic and contribute to confusion. For instance, Harvey, Borowski and Sullivan (2008) describe that the conceptual understanding of 'individual' in social policy discourses is most likely to be formulated as an atomistic, rational being that makes rational decisions. Of particular importance is that such beings are not only abstract, self contained constructions, but they remain fixed identity objects (ibid). Considering the work of Simonton (1992), Harvey et al (2008) thus suggest that a more appropriate construct would be to understand an individual as a unique, living being that, through relationships, continues to co-evolve and have their needs respected.

### **(b) *The implicit social contract***

As previously highlighted, practices of individualized funding are embedded within a neo-liberal political context. Hence, a significant implicit mechanism of this phenomenon is the presence of a social contract in order to support

just and decent lives. Nussbaum (2006), like Campbell (1988), articulates some valuable insights for this discussion which also provide some further explanation of the moral sources of the underlying confusion associated with individualized funding.

In his analysis of John Rawls' (1972) seminal work *A Theory of Justice*, Campbell (1988) contests although Rawls uses tools of thought such as the 'Original Position', the 'Difference Principle' and the 'Veil of Ignorance' to protect the 'worst-off' group in society by social-contract rights instead of autonomy rights, further investigation reveals that people with intellectual disability are not represented in the Original Position. According to Campbell (1988, pp. 91-93), this representation, for Rawls, is limited to those with the 'capacity' to take part in society, that is, to have the minimum requirements of moral agency, they need to "have the capacity to have, and effectively pursue, a conception of their own good", to contribute to the free-market system, and to socially cooperate with other contributing members. These claims are exemplified by Rawls' statements that the main ideas of the 'Theory of Justice' are based upon:

- principles that free and rational persons ... would accept;
- the choice which rational men (sic) would make;
- principles of justice [as] the result of a fair agreement or bargain; and
- symmetry of everyone - relations to each other [which are] fair between individuals as moral persons, that is, as rational beings with their own ends and capable ... of a sense of justice. (Rawls, 1972, pp 11-12)

Within Rawls' theory of justice, people with intellectual disability, with perceived limited or no capacity to be seen as moral agents in this context, then, are constrained to the private arena and destined to be merely passive recipients of care (Campbell, 1988).

Arguing that the full inclusion of citizens with intellectual disability raises questions which must be at the centre of a classical contractarian account of justice and social cooperation, Nussbaum (2006) also expresses concern about the moral exclusion for adults with intellectual disability within the dominant understanding of the social contract:

*For many people with impairments and disabilities, who are fully capable of participating in political choice, this omission from the situation of basic choice already seems to be a defect from the point of view of justice. They are not being treated as full equals of other citizens; their voices are not*

*being heard when basic principles are chosen. The problem seems all the graver when we recognize that many of the factors that sometimes exclude people with impairments from participation in political choice are social and far from inevitable.* (p.15)

As Nussbaum (2006) asks, how does an adult with intellectual disability experience a just and decent life if the moral mechanisms that are needed to support such an attainment are so tenuous in their capacity to deliver? Therefore, how should we respond to the quest for a just and decent life? This should not be subject to the vagaries of another's conception of the good, rather it should be about how a society recognizes the need of belonging of all of humanity, how each unique person has access to adequate provisions by which to experience self-determination, well being and flourishing; how the necessity for dependent relationships is not an antecedent to moral exclusion; and how, within excluding moral frameworks, practices such as individualized funding can lead to ethical inclusion rather than illusion or confusion?

In concluding this discussion, it has become apparent that a transformative domain must be considered.

#### **4. Transformative: commitment to action for social change**

A starting point for transformation is the consideration of 'The Capabilities Approach' (TCA) as described by Nussbaum (2006). As a political doctrine about basic entitlements, TCA "simply specifies some necessary conditions for a decently just society." (Nussbaum, 2006, p. 155) Furthermore, she states, "Failure to secure these to citizens is a particularly grave violation of basic justice, since these entitlements are held to be implicit in the very notions of human dignity and a life that is worthy of human dignity." (ibid) She outlines the characteristics of TCA as:

- Rather than a contractarian approach that only serves individuals, TCA is committed to social cooperation whereby human beings are cooperative out of a range of motives that includes a pursuit of justice, respecting relationships and giving of compassion;
- A sense of responsibility in respecting human dignity, denouncing the removal of personhood based on a lack of autonomy, but rather acknowledging that we are relational beings;
- A revised perception of 'good' whereby it is connected to the realization of a life with human dignity;

- A commitment to responding to the unique needs of people; and
- Encompassing the roles of care and dependency within a conception of justice, rather than ignoring or erasing their relevance. (Nussbaum, 2006)

This discussion has revealed the overwhelming positive benefits of individualized funding practices; however it has also highlighted some considerable constraints that inhibit ethical effectiveness. The relationship between individualised funding practices and the market appears to have some quite significant effects. On the one hand, it promotes a consumerist agenda; while on the other, it serves to sustain a political context faithful to rational individualism. It is this latter effect that is particularly problematic for adults with intellectual disability and their families as it is a context with very distinctive constructions of autonomy, personhood, and the individual. It dictates an expectation of independence and blurs issues of care and dependence. Embedded within a social contract that technically excludes adults with intellectual disability, these constructions are often indicative of the implicit structural constraints within the underpinning systemic responses such as managerialism; monitoring and surveillance of service qualities; and the changing roles of family members and professionals. These situations have compounding effects in the implementation and sustainability of individualized funding practices. If opportunities for self-determination are constrained due to operational aspects such as minimalised 'person' centred planning processes; a lack of real choices and options; and an inability for flexibility of funding according to the changing and unique needs of a relational individual, then the quality of citizenship and aspirations of inclusion become increasingly illusory. Enmeshed in these dynamics, as well, is also an increasing risk that individualized funding practices are perceived by funders and human service practitioners as inappropriate, ineffective and not financially defensible. If we examine the paradoxical nature of implicit moral constructions about capacity, personhood, justice and rights within neo-liberal systems for adults with intellectual disability, we are faced with the dilemma that the contractarian mechanisms we employ to facilitate inclusion, in fact, sustain moral exclusion. We may employ technical processes to support or facilitate capacity for decisional autonomy such as guardianship provisions; however the response to the question 'How ought we respond?' must begin, as Nussbaum (2006) advocates, with ethical transformation towards a capabilities approach.

Other research, though, does provide compelling evidence of the importance of relationships and relational knowledge for positive moral outcomes, that is, when adults with intellectual disability do experience a just and decent life and when a commitment to their flourishing is sustainable. A service type that is particularly effective in supporting this approach is Local Area Coordination; however it is not widely practised, and can even be seen at risk of reduction in quantitative service climates whereby all outcomes need to be measured and reported. Research in this paper would suggest that service responses like Local Area Coordination are critically important because of their capacity to respond to the unique and evolving needs of adults with intellectual disability and/or their families and to engender social cooperation and social capital within communities to protect an individual's right to belong.

In summary, when there is coherence between responses to people's unique and evolving needs; a commitment to fostering a just and decent society rather than merely efficient funding models; and respecting the dignity of all, then a community's capacity to embrace all its members as citizens will be greatly enhanced. Will this be ethical inclusion? Even though this is a question for further discussion at another time, I think we can be confident that we would be a lot closer along the road than we are now!

## References

- Bigby, C. (2007 a). The challenge of implementing state disability policy to achieve second generation rights for people with disabilities. *Just Policy*, 43: 68-75
- Bigby, C. (2007 b). How does the research inform the debate about individualised funding? *Paper presented at the "It's My Money - So What's Different?" Conference, Scope Victoria, Victoria, 13 November, 2007.*
- Boyle, G. (2008). Autonomy in long-term care: a need, a right or a luxury? *Disability & Society*, 23 (4): 299-310.
- Buntinx, W. (2008). The logic of relations and the logic of management. *Journal of Intellectual Disability Research*, 52 (7): 588-597.
- Caldwell, J. (2007). Experiences of families with intellectual and developmental disabilities in a consumer-directed support program. *Disability & Society*, 22 (6), 549-562.
- Campbell, T. (1988) *Justice*, Hampshire: Macmillan Education.
- Chenoweth, L. & Stehlik, D. (2004) The implications of social capital for the inclusion of people with

- disabilities and families in community life. *Journal of International Inclusive Education*, 8 (1), 59-72.
- Clapton, J. (in press). *Ethically transforming inclusion*. Rotterdam: Sense Publishers.
- Clapton, J. (2008). 'Care': Moral concept or merely an organisational suffix? *Journal of Intellectual Disability Research*, 52 (7): 573-580.
- Clapton J. (1999). A Transformatory Ethic of Inclusion: Rupturing 'disability' and 'inclusion' for integrality. *Unpublished PhD Dissertation*. Brisbane: Queensland University of Technology.
- Clegg, J. (2008). Holding services to account. *Journal of Intellectual Disability Research*, 52 (7): 581-587.
- Cumella, S. (2008). New Public Management and Public Services for people with an intellectual disability: A review of the implementation of *Valuing People in England*. *Journal of Policy and Practice in Intellectual Disabilities*, 5 (3): 178-186.
- DiRita, P. A., Parmenter, T. R., & Stancliffe, R. J. (2008). Utility, economic rationalism and the circumscription of agency. *Journal of Intellectual Disability Research*, 52 (7): 618-625.
- Finlay, W.M.L., Walton, C. & Antaki, C. (2008). Promoting choice and control in residential services for people with learning disabilities. *Disability & Society*, 23 (4): 349-360.
- Harvey, O., Popowski, T. & Sullivan, C. (2008). Individuation and Feminism. *Australian Feminist Studies*, 23, (55), 101-112.
- Hutchison, P., Arai, S., Pedlar, A., Lord, J., & Yuen, F. (2007). Role of Canadian user-led disability organizations in the non-profit Sector. *Disability & Society*, 22(7): 701-716.
- Isaacs, P. & Massey, D. (1994). Mapping the applied ethics agenda. *Paper presented to Third Annual Meeting, Association for Practical and Professional Ethics*. Cleveland, Ohio, February 24-26.
- Laragy, C. (2002). Individualised funding in disability services, in T. Eardley and B. Bradbury (eds) *Competing Visions: Refereed Proceedings of the National Social Policy Conference 2001*, SPRC Report 1/02, Social Policy Research Centre, University of New South Wales, pp. 263-278.
- North Shore Disability Resource Centre. (2005). *Guide to Individualised Funding*. North Vancouver: Author.
- Nussbaum, M.C. (2006). *Frontiers of justice: disability, nationality, species membership*. Cambridge, MA: Belknap Press of Harvard University Press.
- Ontario Round Table on Individualised Funding (2000). *Linking individualised supports and direct funding: making money work for people*. Ontario: Author.
- Pearson, C. (2000). Money talks? Competing discourses in the implementation of direct payments. *Critical Social Policy*, 20 (4): 459-477.
- Rawls, J. (1972). *A Theory of Justice*, Oxford: Oxford University Press.
- Reinders, H. (2008). The transformation of human services. *Journal of Intellectual Disability Research*, 52 (7): 564-572.
- Simondon, G. (1992). The genesis of the individual. 1964. In J. Crary & S. Kwinter (Eds.). *Incorporations*. New York: Zone.
- Stainton, T. & Boyce, S. (2004). 'I Have Got My Life Back': Users' experience of Direct Payments. *Disability & Society*, 19 (5): 443-454.
- Stainton, T. (1994) *Autonomy and Social Policy: Rights, mental handicap and community care*, Aldershot: Avebury.
- Swenson, S. (2008). Neoliberalism and human services: threat and innovation. *Journal of Intellectual Disability Research*, 52 (7): 626-633.
- United Nations (2006). *Convention of the Rights of Persons with Disabilities and Optional Protocol*. Geneva: Author.
- Wilson, N., Clegg, J. & Hardy, G. (2008). What informs and shapes ethical practice in Intellectual Disability services? *Journal of Intellectual Disability Research*, 52 (7): 608-617.

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