

Empowerment Through Individualised Funding: Challenges for people with disabilities, service providers and governments.

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Abstract

Individualised Funding is currently regarded as one way of progressing community living for people with disabilities beyond residential models. This presentation sets out to highlight aspects of best practice of Individualised Funding across the world, especially in the USA and Canada, as well as scoping efforts to date in Australia. Key concepts within the practice of Individualised Funding will be explained, and examples of successful models given. The notion of Individualised Funding will be contextualised within progressive disability theories, and criticisms highlighted and addressed. The presentation will present a realistic view of the potential of Individualised Funding to empower people with disabilities who require supports, as well as the many challenges that face all participants in the current disability sector who are interested to move beyond group home models of support.

Introduction

In 2001 we are somewhat stuck in a mindset that on the one hand requires us to acknowledge that services for people with disabilities now provided “in the community” are a massive and positive progression from the institutional facilities we once condemned them to. But on the other that “in the community” does not necessarily mean “of the community”, and that we have lost the impetus to drive power and control over supports into the hands of those who require them.

Many people are struggling to understand what went wrong. We achieved the Disability Services Act, it is now 15 years old, yet the rights statements that underpin it and introduce it in the Principles ring hollow in the face of under-resourced services that struggle to ensure a decent standard of living and some dignity for the people they serve. The idea that a person with disability can have the resources and the range of choices required to enable them to live the lifestyle they prefer is, oftentimes, regarded as ridiculous.

In this presentation I wish to raise people’s understanding of what is meant by the idea of individualised funding, and how it can assist in progressing the

ideals of the Disability Services Act, through the better targeting of resources and supports to the needs and aspirations of individuals.

Introduction to Individualised Funding

The presentation will focus on four main themes:

- What is Individualised Funding?
- How does Individualised Funding work?
- IF as a tool for the empowerment of people with disabilities
- The role of advocacy in establishing and maintaining IF

Individualised Funding is quite a simple and straightforward concept, in that it means that funding is put under the control of the individual, instead of the money being passed from the fund-holders to the service provider agency, which then delivers the service to the individual. It has been defined thus:

The allocation of financial resources to individuals by governments on the basis of their specific, disability related needs and service/support requirements, thereby enabling people to purchase only those services they require (Salisbury *FAQs 2*).

In addition to this definition individualised funding can be viewed as:

- Significant shift from block-funding
- Synonymous with Self Determination
- A “Supply and Demand” model

IF is a significant change from traditional, block-funded service provision.

Current services for people with disabilities are funded to provide support to, usually, an unspecified number of people, who are largely admitted to the service through the admission procedures of the service itself. This is very much a top-down model, where a notional amount of dollars is injected into the disability service system and indexed from time to time, in the hope that it will provide for the many, various needs that are expressed by all the individuals who require support and assistance. In this model the real control is concentrated in the hands of service providers, despite the fact that frequently they are under-resourced by government. The combination of lack of resources, and little incentive to innovate, has led to certain forms of service provision model being favoured above others, and the group home is a good example of this. A tangible result of this system is that the range of needs that can be successfully supported falls within a certain band, and those that lie outside that band are deemed too difficult to support. The system has failed these people.

As well as the under-resourcing issue, there are other shortcomings of the block-funded system. The inability of service providers to be flexible and to really target supports according to the needs and wishes of individual service users is common across the industrialized nations, with consequent lack of opportunity for people with disabilities who use services to develop and grow through experiential learning. The “dignity of risk” is largely missing in traditional services, with group settings requiring an accident and incident prevention approach, or having to react or intervene in group dynamics.

Within this block-funded system we have attempted in the past to address the needs of those individuals who do not easily “fit” into the limited service types that are on offer, or who pose too significant a challenge for service providers working with set amounts of resources. In NSW the 300 Places Scheme targeted people whose needs could not be met without the injection of significant funds into services. Around \$85000 per person per year was made available, and the first significant round of contracting out occurred, to enable the non-government sector to prove its worth as innovative and flexible. However, there were many issues and problems with the 300 Places Scheme, both from the point of view of a service provider, and from the service user’s perspective. In the main, it was a great way to fund non-government group homes, as service providers quickly came to realize that 4 x \$85000 meant one 24-hour staffed house for four people. This was an ironic and unintended consequence for the first meaningful effort to fund people with significant levels of disability as individuals.

One of the problems with the 300 Places Scheme was that, administratively, it was not set up as a genuine individualised funding arrangement. In the first place, it maintains what are described as “third-party” payment arrangements. Even though the funds are individualised they are paid directly to the service provider, and do not pass through the hands of the person with a disability or their representative. Individualised funding, in its purest form, requires that some control over the funds, including the option to hire their own personal assistants, be provided to the person who needs support. However, it is not uncommon in Australia for third party arrangements to secure much more targeted, individualised support responses, as is witnessed by the entire disability system in Western Australia. The greatest problem for the 300 Places Scheme was that it treated the individual payments to service providers as if they were additional services themselves, within the same service contract format, and locked into arrangements with providers that were difficult to remove people from. The planning and innovation came from the service providers, rather than being planned externally, and therefore became quickly framed by the same limitations that affected all other members of that service.

The model of Individualised Funding that is being promoted across the USA, Canada, and now the UK, has Person-Centred Planning at its core. The

diagram indicating how funds are allocated in an individualised funding arrangement show how central and important the ultimate service user is, and the range of choices that opens up when funds are allowed to go through their hands. This represents a direct funding model, and has been criticised for on a number of fronts, from government departments concerned about the proper acquittal of such public funds, and from disability advocates, concerned that this model places too much responsibility on the shoulders of the person with disability to manage her own funds and supports. Such tasks become increasingly difficult for people who have significant cognitive impairments. However, later on in the paper I shall look at other models that address these concerns, yet utilise the same principle and, most importantly, the same channels for the resources needed to purchase supports.

The relationship between IF and Self-Determination.

Last July I attended the first international conference on Individualised Funding and Self Determination in Seattle, entitled “Freedom Funding Citizenship”. The linkage between individualised funding arrangements and Self-Determination is very strong in the USA, as the latter has given its name to a number of service-focused projects around several states, which aim to increase service user control of the supports they receive. Some of the issues raised at the conference remain a challenge to many of us, especially around the limits that might sensibly be drawn around what constitutes a necessary support, and the extent to which people can be entrepreneurial in the use of public funds. Issues such as homeownership, the purchasing of luxury cars, and securing businesses, by which to establish a valued career as well as a steady income stream were discussed by several of the American delegates, and these challenged those of us who were there more out of a concern for social justice matters. In most jurisdictions, however, the Self Determination movement is a means of focusing attention on the significant change in the way that disability services must be provided to ensure the core principles of freedom, authority, support and responsibility.

Importantly, whilst we in Australia, like most other industrialised nations, have not seen the need to articulate a movement like Self-Determination, we do, however, value the principle of self-determination as one of the key aspects of respecting people’s human rights. Both at the national level, where we believe in a population’s right to self determination, in relation to governing itself, and at the individual level, as an underpinning principle to all the rights of expression, association and decision-making. Most importantly, for those attending this conference, it underpins the rights articulated in our Disability Services Acts, and is a key element in the empowerment of people with disabilities who use services.

This leads us to the question of how to operationalise self-determination within disability services, and hence empower people. Firstly, and probably

most importantly, there is the process of planning, which is covered by our Standards, but which currently remains the domain of service providers. Later on I will demonstrate how this can be altered to improve the quality of planning. Secondly, there is the practice of enabling users of services to express choice, and of service providers to enable, facilitate and then respond to these choices once made. This is currently very difficult within our current organisational arrangements, where staff is ultimately more accountable to management than they are to service users. Individualised funding arrangements significantly alter this dynamic. And thirdly, and this was discussed widely at the conference, the notion of risk-taking. The Conference Declaration stated the following principle:

“Policy and practice must acknowledge and honor risk-taking as an essential element of self-determination and an important part of life” (Dowson and Salisbury 2001. 15).

The principle of risk-taking appears to me to be central to the idea of organizing and running supports for yourself. When I visited with recipients of individualised funding in British Columbia, during their struggle away from the institutional or group home setting in which they found themselves they were invariably confronted by service providers and funding bodies who were afraid of the consequences should any injury or death occur when “out” in the community. Some arrangements had to sign over the responsibility for such events to the person to enable providers and funders to allow supports to take place at home, rather than in a controlled setting, and these were written into the contracts. The important thing to note is that the service recipients were happy to sign over this responsibility to themselves, as it enabled them to have control over even more aspects of their lives, including those which had life or death implications. This remains a challenge to us in Australia, not just to service providers and funders, but also to advocacy groups and the population at large, for whom the link between disability and vulnerability has been promoted too strongly, in my view.

IF operates on a “supply and demand” model.

One way to look at individualised funding is as a supply and demand model. In the block-funded system, the supply side is favoured, with service providers (the suppliers) being granted funds with which to deliver the service they choose to those who require services (or those who “demand”). Those who support a move to individualised funding arrangements believe that to deliver quality services that are actually going to meet people’s needs, funds should be granted to the demand side of the equation: in other words to the service users themselves. This is a fairly standard, economic equation.

It is somewhat ironic that we are still so far away from considering placing funds in the hands of service users themselves in this country, yet for years

we have been utilising the language of a consumerist economy. We have termed the users of services “consumers”, or even “customers”, yet we have never provided them the means with which to activate the limited rights that are afforded to consumers in a market economy. The provision of individualised funding arrangements will enable people with disabilities to activate these consumer rights, whilst other, social justice and human rights need to be fought for at a political and social policy level.

How does Individualised Funding work?

- Develops many innovative models that encourage community involvement
- Breaks down the complexity of service provision into component parts
- Builds in independent roles to enable consumer empowerment
- Changes relationships between players in the system

IF is a principle that enables a number of different models and types.

There are a number of models, potentially as many as there individuals who receive IF. But I will concentrate on three:

- Direct Payments
- Brokerage
- Microboards

Direct Payments

Direct Payments, as a concept, is fairly self-explanatory. It is a system whereby people with disabilities have the funds they require to purchase supports paid to them, and it is largely up to them which providers they use and which types of support they have access to.

Direct Payments is the preferred model of funding of the UK Disabled Persons Movement, for obvious reasons. It puts the control over funds for services and over those who provide support totally in the hands of the service user. It is open to criticism because of the perception that people can purchase things as they please, and perhaps are not as accountable as services might be in the spending of public funds. It is also criticised for not being as accessible to people who might not have the skills to manage both complex contractual and funding agreements, and the management of staff.

Whilst direct payments implies strongly that the control and the responsibility are now in the hands of the person who uses the supports, it is important to recognize that some assistance with the tasks of managing budgets and people may be required. This is especially true when individualised funding is being introduced for the first time. Demonstration

projects should be established that provide support and advice to people who want to individualise the funds that are expended on them in congregate settings, and who may require some advice on how to meet contractual obligations, negotiate for better funding options, choose service providers, employ and manage staff, and manage payroll and budgets.

Microboards

This is formed when a small group of committed family and friends join and form a non-profit society around a person who has particular needs for support. The group addresses the person's planning and support needs in a way that ensures maximum control by the person for whom it is created. The creation of this society is for one person alone. The Microboard takes responsibility for receiving, distributing and acquitting the funds that come from the funding body for the use by the person with the disability.

The numbers of people who must sit on a Microboard will depend upon the legal requirements of the jurisdiction about what constitutes a legal non-profit society. In terms of its workability, between 5 and 7 is a good number to keep it dynamic and not too unwieldy and bureaucratic. The person themselves can be one of these board members.

The tasks of the board members would vary according to their skills and talents. Obviously the roles of President, Secretary and Treasurer have to be filled. But other skills like management and staff liaison could be of great use too. However, of greatest importance is the role of friendship and spending time with the person, as this leads to real relationships and important knowledge about what the person's wishes and needs are, and the best ways to meet those needs and wishes.

Microboards have been especially useful in organizing and managing the supports to people with complex and high support needs. They provide a solid infrastructure when a person with significant support needs prefers to employ their own staff, rather than purchase packages of support from formal service providers. Often people who access microboard provisions are those for whom the service sector has not worked, or who find it hard to be placed within a service because their impairments are complex or difficult.

A good introduction to Microboards and how they work is available online (Perry 2000).

Brokerage

Brokerage refers to a process whereby a person with a disability employs a person to assist them with the processes of planning, getting resources and then hiring and reviewing the quality of service providers. The task of

organizing an individualized funding arrangement can be quite complex, and sometimes difficult and tiresome for an individual. The services of a broker, as long as they are provided independently, can be of considerable benefit.

Brian Salisbury, one of the two conference organizers and authors of the Conference Report, is an independent broker who was involved in the first IF model, the Woodlands Parent Group in BC (started in 1976, when the closure of the Woodlands institution provided an opportunity to implement individualised funding arrangements for those who were moving to community settings). Brian indicated the roles and functions of a broker:

- to provide advice and information
- to assist in reviewing and clarifying lifestyle needs and expectations
- to develop and/or review personal plans
- to negotiate individualised funding
- to locate, arrange, monitor and evaluate community services and resources (specialist and generic, and those that can manage IF)
- to resolve and mediate problems
- to help modify existing services and stimulate the development of new services (Salisbury 2000)

In NSW we have just introduced a new Disability Service Access System. This system is not brokerage. However, it involves independent Support Planners in the drawing up of support plans for people with disabilities. These support plans are drawn up over a period of about four weeks, and are submitted to the Ageing and Disability Department, who then provide the funds, and suggest service providers who can deliver the necessary supports. This is at least a step forward in diverting funds according to need toward not only service providers, but also to other people in the community who might be able to perform a supportive role. The new system definitely supports the principle of diverting funds to other community agencies than just the current service providers. At the moment it limits these independent players to a planning role, and this does not yet even include a role in the review of service quality and change in circumstances. However, as the system grows, and becomes the primary mechanism for injecting new funds into the system, the potential for an expanded role of Support Planners into brokers, increases.

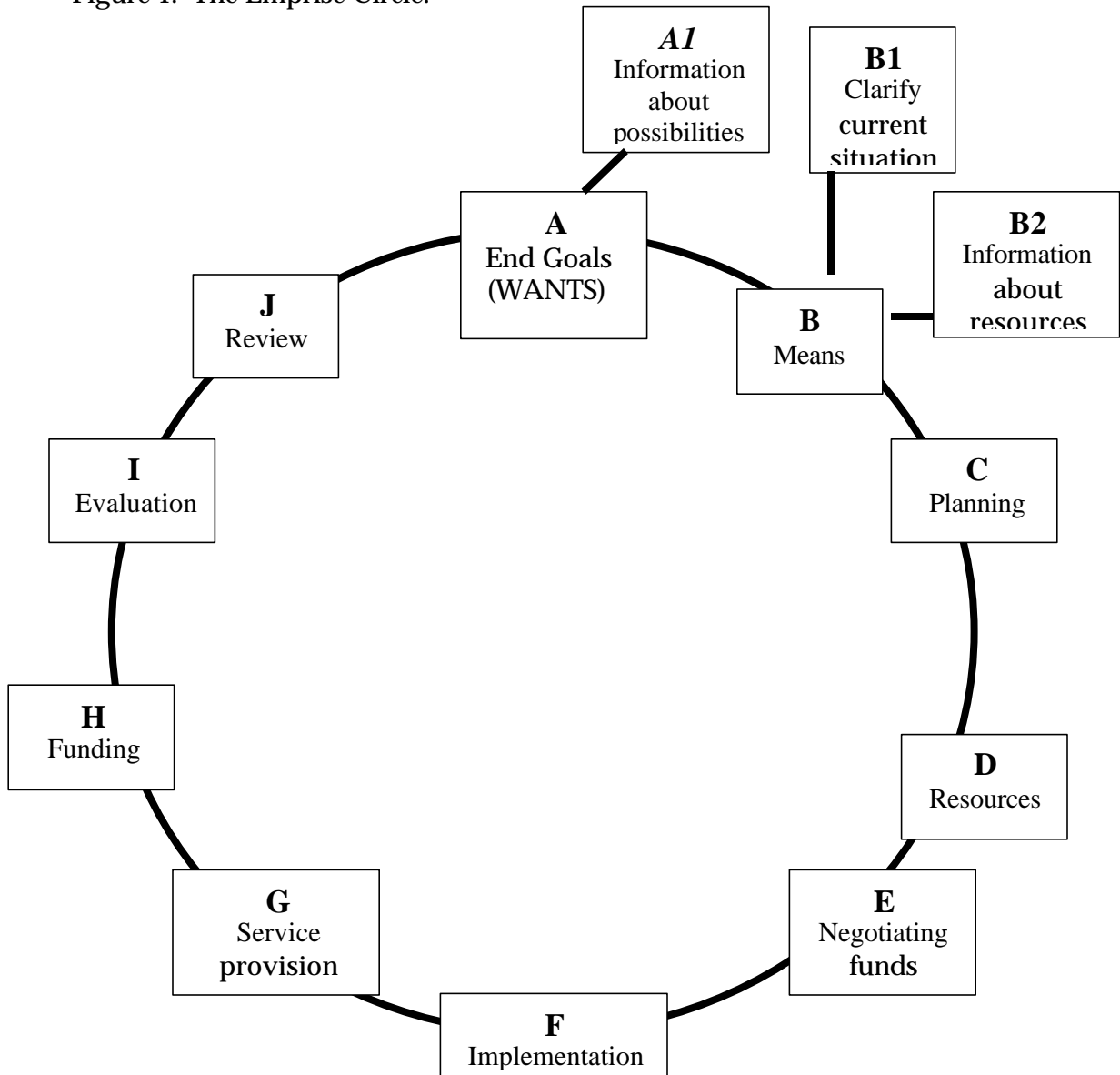
The component parts of the disability services system.

The EMPRISE model (Figure 1), devised by Steve Dowson (1999), is an excellent tool for analyzing the complex web of organizational and personal relationships that go to make up a support arrangement.

The paper that this is drawn from is available at the website, and really gives an excellent introduction to the mechanics of IF, and why certain models will work better than others. One of the things it illustrates well is the explicit role

separation that must exist if individualised funding arrangements are to work.

Figure 1. The Emprise Circle.



(Dowson 1999)

The separation of roles is crucial in an ideal individualised funding arrangement. In such an arrangement steps A, B, C and J are under the control of the service user. In other words, those parts of a support arrangement which determine what gets done, for what reason, and then evaluates the success or otherwise of the support based on criteria set by the person in receipt of the support. The role of the service provider is limited to G, and is responsive to the needs and wishes of the service user, and

dependent upon funds supplied by the funding body, which have been negotiated on the basis of a plan, and assisted in many instances by a broker (who has a role to play in steps C to F). The tasks of evaluation of support, based on value for money and the honest fulfillment of contractual obligation, are contained in I, and separated from the task of the qualitative review (J). This represents a move away from the standards based assessment that we see across the board in NSW, where individual outcomes do not accurately get evaluated.

The newly configured roles lead to a fundamental shift in the relationships between the various players.

The role of the service provider is obviously much less dominant within the IF arrangement. The roles that a service provider plays are less numerous, and less involved in either the planning or the evaluation of the supports. Most importantly, it is not the decision of the service provider as to who gets a service I the first place. There is far greater potential for the individual who requires the supports to decide on what supports are needed in the first place, how these supports should be delivered, and to maintain some real role in controlling those supports throughout the process.

Challenges posed by Individualised Funding

Challenges to funding bodies.

Funding bodies face the greatest challenges if individualised funding is to be introduced in any meaningful way. Amongst the issues to be faced are:

- “Unbundling” block-funded services
- Ensuring equity whilst determining resources according to need
- Maintaining standards within the purchased service sector
- Linking support payment to basic income security payments
- Considering payment to family members.

“Unbundling” block-funded services. This terminology relates to the transition that will need to be made by funding bodies, from the provision of block grants to service providers, to a much more open contractual system whereby people with disabilities in effect “purchase” the service of their choice, leaving service providers dependent upon this choice for the bulk of their funding.

Government departments will be the ones who decide to move forward toward individualised funding, and David Young, a senior bureaucrat within the province of British Columbia, has advocated Mixed Model Funding as a way of making this difficult transition. This would maintain some funds to ensure service infrastructure, and to continue a broad planning and strategic role for the state disability services, at around 20% of a service’s costs. The

remaining 80% would come from direct funding dollars, the funds to the demand side. David sees three steps to achieving this mixed funding model:

1. Community living services to renegotiate their contracts to include a larger variable amount in their annual budgets. This money would be forthcoming from the provision of supports, for which services would bill the government. This is very much a third party arrangement, where the funds do not go directly to the service user. The step allows the agency to gauge whether or not it is structured to meet these different funding demands, and gives it time to adjust.
2. Provide funds direct to the individual, in the most efficient way possible. Possibilities include going through the social security system, or the use of smart cards, which contain funds and can only be used for specified purposes with approved agencies.
3. The development of guidelines for purchasing services outside of the formal service sector. Greater choice needs to be balanced by consideration of how quality and standards can be maintained outside the jurisdiction of the formal sector (Young 2000).

Ensuring Equity. The notion of equity is often raised when individualised funding is discussed, mainly because the amounts committed to individualised funding arrangements are frequently higher than those allocated to block-funded agencies. This holds true across the board, in both accommodation and day options, but is more symptomatic of the under-resourcing in the past of disability services in general. The resources committed to the block-funded system do not generally enable the sorts of individual outcomes that are required by the Disability Services Acts. Individualised funding arrangements will require that more funds be expended to enable individual outcomes, yet will provide more equity and accountability for how funds are spent as resources begin to be tied to targeted strategies. Economies of scale may well be possible down the track, and these are likely to be in the form of shared outcome-based resources, as opposed to being tied up in the administration of large, service organisations.

Maintaining Standards within the Purchased Service Sector. Regulating an essentially less regulated service sector will be challenge. However, this challenge is already underway, with the massive movement toward contractual arrangements between government departments (purchasers) and non-government and private service providers. In NSW the Disability Services Standards have been criticised for not effectively monitoring service outcomes for individuals (NSW Law Reform Commission 1999), yet there is scope for the Standards to form the framework for a general accreditation system for disability service providers. Scrutiny on individual outcomes

should come from robust contractual and individual planning processes for each individual.

Linking Support Payments to Basic Income Security Payments. This is one possibility for government departments to consider. It relates mainly to the principle of direct funding, but has wider implications for the perception of specialist disability funding as a right and an entitlement. By bolstering the basic Disability Support Pension, and making it responsive to the specialist support as well as the basic income needs of an individual, a completely different administrative landscape would emerge. The barriers between Commonwealth and State bureaucracies would need to be dismantled, and the responsibility of the State departments would be to assist in the administration of service provision, rather than funding per se, and managing the interface between individual, services and departments.

Considering Payment to Family Members. A very controversial issue, but one which is being lobbied for increasingly in Canada and North America. Individualised funding makes it feasible to pay ordinary members of the community to work closely with an individual, and in some circumstances this person might have to be a member of the person's immediate family. The rules that disbar family payment are mainly there to prevent rorting (i.e. cheating) of the system, and also because "carers" often receive an allowance that represents a recognition of their role. If the previous suggestion of linking the allowance systems to the disability support funding, then the latter barrier is lifted.

Challenges to Service Providers.

Service providers too are nervous about a radical transition to a demand-led system, some with good reason. Individualised funding provides an opportunity for service users to take their funding elsewhere if they are not satisfied with the standard of service they receive, or if they believe that their concerns are not being addressed. Other concerns include:

Ongoing service viability. The most concern about individualised funding expressed by service providers is that of ongoing viability. This is hardly surprising, as what is effectively being offered is the removal of the certainty of block grants, and the competitive environment of smaller, less secure individual funds. The strategies to "unbundle" block funds, mentioned in the section above, will begin to address some viability issues. However, the reality will have to be faced, that services which do not provide supports that are demanded by people with disabilities and their families, will eventually lose funds and cease to operate.

Contractual complexity. Another area of added difficulty and complexity is the proliferation of contracts that individualised funding requires, and this affects

service providers as well as funding bodies. When I was over in British Columbia there was quite a lot of angst about a process of contract reform that was underway, by which the government department was hoping to consolidate a large number of individual contracts that were held by large agencies into one block contract. Many supporters of individualised funding felt that this was a step backwards, but it remains to be seen what the impact of that reform has been.

Delivering Flexible supports. At one and the same time this will be immensely difficult for some agencies, and relatively straightforward to others. We have been talking flexible and responsive services, individual choices and focusing on the person for years. However, we have become constrained by a limited number of service models and types, with the added problem of insufficient resources. Individualised funding does raise the stakes for service providers to raise their game and become much better at responding to individual need. On the other hand it really demands that service providers listen to what they are being told to do by the service users and their representatives, and to respond accordingly. With planning being done externally the responsive services will be successful.

Improving quality within existing resource constraints. The introduction of individualised funding does not necessarily mean that the funding base will be expanded. There is, I believe, the potential for individualised funding to have some impact on deciding equitable support packages for individuals down the track, once it helps to establish the real costs of providing support in the community. However, one thing that individualised funding does do well, is increase the resource base that is informal or not funded. By placing the funds in the hands of people with disabilities, their entrepreneurial skills in making a scarce dollar go around in ways that suit them has indeed meant that in some instances funds have been paid back to the department at the end of the year:

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

Roger's ability to repay funds to the department is evidence of how the individualised funding approach empowers people to take pride in delivering services for themselves in the most efficient manner. His willingness to do this meant that funds were freed up to be used by another individual.

Challenges to Individuals.

The challenge to the individuals, people with disabilities and their friends, families and allies, is to make individualised funding happen. Successful and consumer-controlled individualised funding is rarely achieved by government departments conferring it upon those who require supports, unless it is part of a wholesale system change. Direct lobbying is required firstly to establish individualised funding as part of a reform agenda, and then to ensure it is implemented as a response to the needs and wishes of people with disabilities, rather than as a pilot “model” of service delivery, that aims to showcase service provider innovation. To ensure stability and equilibrium within the complex circle of support that individualised funding seeks to establish, parties that are committed to the individual must continue to lobby for their well-being.

A significant challenge to individuals, and to those who represent them, is to manage the complex affairs and contracts that go together with being a recipient of government funds, and, in many instances, with being an employer. As well as the need to understand how to hire and fire and manage staff, there is a strong requirement for people with disabilities to do this well, and with due regard to legal levels of wages and conditions. The potential for IF to abuse workers’ rights has been raised (Pratt 2000), and the industrial relations framework in the USA and Canada do not make solutions easy. Governments have been complicit in driving people with disabilities and their families to paying below legal wages, and enforcing dangerous conditions, because of the lack of funds granted, and there being no recognition of adequate wage levels when funding is granted. I have argued (Bleasdale 2000) that the Australian industrial system allows for the setting of awards, and that it may be possible to amend the Social and Community Services Award of the Australian Services Union to reflect individualised funding arrangements. However, this must be done keeping the integrity of wages and conditions intact. My argument is that by formulating such an award we can assist in the negotiation of adequate funds, by establishing a realistic hourly rate for support.

Amongst a range of challenges that face individuals I would finally like to focus on the notion of risk. As mentioned earlier, governments in Australia are not comfortable with conferring the risk of living in the community upon either service providers or service users. Despite having the dignity of risk written into the Disability Services Act, the safe option is almost always preferred. Service providers have no place to lobby government departments to enable them to take risks on behalf of service users, and to render themselves immune to prosecution for negligence, especially in the face of continuing evidence of abuse and death in congregate care facilities. However, people who have significant levels of impairment, yet who wish to

lead a life in the community, despite the risks that such a life may pose, need to press for the right to take that risk on for themselves.

The Role of Advocacy in establishing and maintaining IF

The theme of this paper has been how individualised funding can help to empower people with disabilities who use services. The major vehicle for the empowerment of people with disabilities in Australia is the advocacy movement, and this section will speculate as to the potential involvement of this movement in the push for, and the administration of, individualised funding projects and arrangements.

There is, I believe, a very important role for advocacy to take in establishing individualised funding as a viable service/funding option for people with disabilities, and maintaining its effectiveness. This role can be broken down into several constituent parts:

- the promotion of Self-Determination as the guiding principle of both service specific and social/community inclusion aims
- the continued push for entitlement to service provision, that is based on identified needs and wishes, and targeted at individuals
- the continuing need to address systemic discrimination and other barriers that exclude people with disabilities **outside** considerations of service provision
- taking on roles that are directly involved with the implementation of individualised funding for people with disabilities.

Promotion of Self-Determination as guiding principle of service specific and inclusion aims.

There appeared to be agreement at the conference on the capacity of individuals to be better equipped as citizens to enjoy their rights and to fight the prejudice that they encounter through the supports provided by individualised funding arrangements than in block-funded service options. Individualised funding can certainly provide far greater opportunities for self-esteem and control on the part of those who receive services. This was regarded at the conference as a pre-requisite for enjoying citizenship. The guiding principle of individualised funding services would appear to be Self-Determination, and, as has already been pointed out, this also underpins the Principles of our Disability Services Acts.

In relation to Advocacy, there appears to be reluctance in Australia to advocate for any service type, probably based on suspicion of services by people with disabilities and their allies due to past malpractice. However, it is fairly clear that most successful individualised funding arrangements have been fought for, and have had committed people, often family and friends,

continuously involved in the lives of people with disabilities. This is a continuing advocacy role. The participants in Microboards are advocates. There is definitely a role for advocacy to play in promoting individualised funding as a viable and necessary next step in the community service continuum.

Continued Push for Entitlement.

If we are to adequately address issues of eligibility and properly assessed need, let alone adequate funds, we need to push for entitlement to necessary supports through whatever means possible. In the past I've advocated for a constitutional Bill of Rights (Bleasdale, Crumpton, Hardaker and Tomlinson 1996: Bleasdale and Tomlinson 1996), even a statutory bill of rights, which would set out what citizens of this country have a right to expect. Clearly grand-scale systemic solutions hold the key to the question of entitlement. However, something as individual as individualised funding can help in developing solutions that are successful and more closely directed toward need. Currently we are reluctant to seriously lobby for a doubling of disability funding, presumably because we are not certain that the types of service responses we have provided in the past are guaranteed to solve the "problem" of supports for people with disabilities. If individualised funding can generate good quality outcomes that people with disabilities are actually happy to promote a best practice, then that will help toward generating the political will to ensure that entitlement, and the resources to support it, at least gets onto the agenda.

Need to address systemic discrimination.

Much advocacy needs to be directed toward the community and toward our political institutions. The principle of equal access does not necessarily include the specialist service system. Rather our efforts need to be channeled toward reducing discrimination, and ensuring that the entire community is accessible and inclusive of all people with disabilities. I think that the reluctance of much of the Disability Movement in the UK in relation to embracing IF is due to the perception that it is all about solutions through the specialist service system. There is perhaps too much emphasis on the part of some IF advocates for achieving all the citizenship goals of people through IF, through the specialist service system. I believe that, while advocacy has a role to play in promoting IF and seeing it succeed, the principle role of advocacy must be to maintain its focus on changing the broader community.

Taking on roles that are directly involved with the implementation of individualised funding for people with disabilities.

In the past advocates have striven to ensure that a very obvious distance remained between themselves and the activities of service providers. There has been a reluctance to engage with any part of the service sector, despite

members of the advocacy movement being perhaps best placed to plan for good quality services having been so used to experiencing the poor quality ones. The explicit separation of roles within the individualised funding circle allows for advocates to become involved at a number of levels, while remaining always apart from the actual role of service provider. For example, within a Microboard, the board member would be an advocate or family member, yet if they were required to do some actual support, they would step down from that management position and another would replace them. New funding models need to be introduced as demonstration projects, and advocacy groups, particularly those involved in group or systemic advocacy, would be ideal agencies to oversee what is essentially a person-driven system. Like in British Columbia, a state peak body could oversee a project which gave support and advice to individuals who receive direct funding.

Conclusion

Individualised funding provides opportunities to people with disabilities to achieve control over the supports they receive. Empowerment within services is important, especially for those whose needs are complex and many, as the time spent with assistance is often great. Having real control over these supports will significantly and positively impact upon the quality of the lives of people with disabilities. However, and this remains a challenge for supporters of individualised funding and the wider movement of people with disabilities, the real barriers to empowerment remain within the community, and the acid test for individualised funding is whether or not it can assist people with disabilities to interact more successfully and meaningfully with the community. Here are the reasons why I think it will:

- Individualised funding enables the person to direct supports in ways that the person wishes – assistance will be given IN the community
- Individualised funding arrangements encourage “natural” circles of support, with family and community members
- The choice provided by individualised funding will render institutional and congregate care redundant
- People with disabilities will use their supports to engage with the societal institutions of family, education, employment, politics, religion and social life.

So, in conclusion, whilst individualised funding should never make the claim that service provision will lead the way toward full inclusion of people with disabilities in our society, it does represent the best opportunity for empowerment within those specialist supports for those who use them. And these supports can, in turn, be more focused on assisting people with disabilities to engage in and WITH the community.

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