AN OVERVIEW OF ISSUES IN THE IMPLEMENTATION OF INDIVIDUALISED FUNDING

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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 be 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 is 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 Campain (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 planning 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 lifelong 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 Vizel’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 a an exemplar policy area (http://www.partnersinpolicymaking.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 examples 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 qualitative 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 one 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


