Submission to the Productivity Commission's Disability Care and Support Public Inquiry

Individual Funding Models

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This paper provides a brief overview of my research into individual funding models and the factors identified which contribute to successful outcomes. Further information can be provided if required. Overall, people with individual funding reported their quality of life improved and they enjoyed greater control over the services and supports purchased compared to when they received traditional agency managed services.

Individual funding models

Individual funding models allocate a specified amount of public money to support a person with special needs. Their implementation is complex and models vary greatly across countries and states, and from program to program. The differences stem from differences in values, culture, existing practices and change management strategies. This paper illustrates differences by referring to models in Sweden, the United Kingdom (UK) and Victoria. Western Australia has used Local Area Coordination for two decades (Bartnik & Chalmers, 2007), and much can be learnt from there. However, as I do not have first hand experience of Western Australian services I will not comment on their model.

I conclude that it is both practical and effective to have a range of individual funding models coexisting to provide people with choice as to how much control and responsibility they want. Sweden provides an example of how this can be achieved. For individual funding to achieve successful outcomes, there needs to be adequate funding; available information and support services when required; appropriate services to purchase; opportunities for social inclusion, and suitably trained and supported support workers.

Swedish and UK models

I worked at Jonkoping University Sweden for six months in 2006 and during that time interviewed government administrators managing disability services and cooperative staff supporting people who lived independently. In 2005, I spent four weeks in the UK visiting independent living centres and interviewing government personnel in different levels. Services supported people with all types of disabilities in both countries.

In Sweden, the acceptance of a social democratic state with high levels of taxation resulted in well funded social services. The *Support and Service for Persons with Certain Functional Impairments* Act, LSS (1994) gave people with a disability an entitlement to live independently in the community with support, and public housing was available when required. An assessment of personal support needs led to an adequate individual budget to support independent living in the community. There was considerable discretion as to how the funds could be spent with minimal oversight by authorities. Funds were used without question for holidays and social participation activities. While most countries tie funding to formal planning processes which are reviewed for accountability, Sweden defined citizenship in terms of having the right to a full and active life with minimum government interference. Formal planning processes were widely viewed as unnecessary and intrusive, and generally avoided because they were thought to impinge on citizens' rights.

Sweden had four models for managing the allocated funds: self-management, cooperatives, for-profit or not-for profit agencies, and tradition services provided by the municipality. In 2006, only 3 per cent of people took full control and directly employed their own staff; 12 per cent allocated their funds to a member based cooperative, which became the legal employer of support workers; 25 per cent allocated their funds to a for-profit or not-for-profit organisation which became the legal employer; and 60 per cent transferred their funds to the municipality which provided support services (JAG Sweden, Jämlikhet Assistans Gemenskap, 2006).

There was an expectation in Sweden that people with a disability would follow the social norm and move out of the family home when around 20 years of age. People with a disability generally moved to flat and some people with an intellectual disability chose to move to a small group home available in some areas. People with an intellectual disability generally attended a disability day service and 'independent living' referred to having personal assistance at home in the evenings, weekends and during holiday periods. Adults with an intellectual disability needing support and oversight to manage their affairs were appointed a ‘trustee’ (Överförmyndare) by the municipality: this person was often a family member.

Individual funding in the UK commenced with the Direct Payments Act 1996, which gave people with a disability the right to directly employ support workers. Funds were limited and their use was restricted to employing support workers. Recipients, or their representatives, were fully accountable for all funds and they carried all employer responsibilities. Few people took up this restrictive and demanding option and subsequently the alternative ‘Individual Budgets’ model was developed and became more popular. Assessment and accountability procedures are more relaxed and funds were used more flexibly for social support. The term ‘independent living’ had a different meaning in the UK to that in Sweden. Most people with an intellectual disability in independent living in Sweden attended disability day services. However, in the UK the term was used when people wanted to avoid formal disability agencies. This distinction appears to have blurred in recent years as UK disability agencies have developed new ways of responding to people with individual funding.

The different Swedish and UK models of individual funding reflected their different underpinning political philosophies and legislation. Sweden financed its commitment to social democracy and citizenship rights with an entitlement to resources and a less intrusive approach to accountability. The UK provided limited resources and placed greater emphasises on individual responsibility and accountability for public money.

Australia

In some Australian states there is a move away from block funded disability services to individual funding, with a plethora of models for distributing the money and supporting the person. Generally services and activities can be purchased from outside traditional disability service agencies. Australian individual funding models are similar to the UK in that they provide limited funds and have high levels of accountability for public money.

Victorian models

I worked for the Victorian Disability Services, Department of Human Services until 2005 and was involved with the evaluation of early individual funding models (*Futures for Young Adult*s, *Support & Choice* and *Direct Payments*). Later I evaluated the *Individualised Funding Project* at UnitingCare Community Options (Laragy 2008) and I gathered data in Victoria for the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) study of individual funding (Fisher et. al 2010).

In Victoria, where the Government has developed and implemented individual funding policies over the past decade, the number of individual funding models is increasing. New services are emerging in response to individual funding and one I studied was Karden Disability Support Foundation in Ballarat. This foundation was established in 2006 and was more flexible and adaptive to people's needs than any established service I know in Victoria. A distinctive feature is the support provided to its staff. In comparison to this rapidly expanding foundation, many established disability support agencies are struggling to reorientate existing organisational cultures, practices and strategies.

Conclusions

Individual funding is welcomed by people who want more control and choice over their services. People reported that they could utilise funding more effectively when they controlled spending, and they liked having access to more funds by using less case manager services. While the benefits for those who want individual funding are clear, there are issues needing to be carefully managed.

Inadequate funding is one concern. Previously case managers distributed pooled funding among their clients to those they perceived as having the greatest need and to deal with each crisis as it arose. As funding allocations were often inadequate, moving funds to the person with the highest need 'kept the system afloat'. Although individual funding provides greater transparency and recipients generally feel more empowered, there are no funds available for emergencies and in Victoria it takes many months to organise a reassessment of need. If funding is inadequate, individual funding increases the risk of people being left without necessary supports.

Isolation and lack of support is another concern. Families I interviewed using individual funding to support a child with a disability tended to become isolated over time. Gaining necessary support and information at points of transition or crisis was difficult. In theory these families could have purchased case management support when needed. However, with inadequate budgets, and no easy access to case managers, most struggled on alone.

The protection of vulnerable people is a challenge for all disability services and individual funding offers both added safeguards and additional threats. Some people found that selecting and establishing a good relationship with support workers offered greater safety to themselves or their family members compared to strangers sent by agencies coming into their home. However, there is also the potential that vulnerable people may be exploited with less case management oversight. In the individual funding models I studied there was always a high degree of review and no instances of abuse reported, although I note it is mentioned in some international literature. Finding an acceptable balance between freedom to choose and protection will continue to be a challenge, and clearer guidelines are likely to develop over time in Australia as experience of individual funding increases. Western Australia may be able to contribute in this regard. Sweden’s less controlling approach may not be acceptable in Australia. Victoria has adopted a highly detailed planning and review process which is cumbersome and resource intensive. I hope that a more streamlined approach will be developed over time.

Individual funding is challenging many established Victorian agencies because it requires major changes to philosophy and practices and it presents new risks. Agencies and case managers have less control while still feeling responsible for their client’s welfare. Furthermore, service systems have to change radically, especially financial systems which were not designed to provide individual accounts. The adaptability of existing services to individual funding varies widely and it seems likely that some agencies will flourish and others will flounder.

The success of individual funding depends on suitable support workers being available. The FaHCSIA (2010) study found that individual funding resulted in improved workers' conditions with more stable employment and improved relationships with clients. I heard similar reports elsewhere of greater flexibility making it easier to recruit support workers. However, I have also heard that workers are not always available and they can be exploited. This is an important area needing more study.

In conclusion, Sweden provides consumers with a choice of four distinct models of individual funding to meet individual needs and preferences. The four models provide a framework that could be adapted in Australia. Such a framework would provide general guidelines for service development without being overly prescriptive. While Australia will not provide the quantum of funds available in Sweden, individual funding needs to be adequately funded to ensure basic needs are met and people are not left isolated, especially in times of crisis. My studies show that there needs to be information and support services available to inform choice and that adequate, but not overly intrusive review mechanisms are needed to ensure vulnerable people are not exploited or abused. Existing agencies need support to transition to individual service provision. Finally, more work is needed to understand how individual funding impacts on the workforce. This is important because people with a disability are dependent upon these workers and because the workers are important, be they support workers, case managers or those in the new roles of planners, facilitators and financial intermediaries.

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6 July 2010

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