Submission to the State and Federal Government Disability Services

Community Consultation Results about the Introduction of Individualised Funding or Self Managed Care

Authors:

Monika Baker (BSSC-HS/ACE, Hon AVET)
Craig Zubrinich (Student Disability Studies at Flinders University)

Disability Advocacy and Complaints Service of South Australia Inc.

3/178 Henley Beach Road

Torrensville SA 5031

Phone: 08 8234 5699; Fax: 08 8234 6044;

email: drigney@dacssa.org.au

Introduction

The Disability Advocacy and Complaints Service of South Australia Inc. is a Commonwealth funded disability advocacy agency, which is managed by a Board of Management of people with disabilities. Our agency is part of the National Disability Advocacy Program funded by the Department of Families, Housing and Community Services and Indigenous Affairs (FaHCSIA).

Disability Advocacy and Complaints Service of South Australia Inc. is funded to deliver individual and systemic advocacy to people with disabilities and their families. Our clients come from all socio-economic backgrounds. Anyone with a disability, including anyone with a mental health problem, can access our service if they have a complaint or grievance related to their disability.

Wherever possible we act on the expressed wishes of the person with a disability.

After many people approached us over the years, asking whether we can do something to get them into a self managed care system. Recently we heard that the Minister for Disability Services, the Honorable Jay Weatherill, had visited the UK to gain information about the system and he announced that in a few weeks we would have access to individualised funding. We decided that it was time to undertake more widespread community consultations about this issue.

The South Australian Council of Social Service supported these community consultations. The Policy Council of SACOSS will use the results of these consultations to develop a position paper on Self Managed Care/Individualised Funding.

The Physical Disability Council of South Australia also made a contribution to the consultations and supported our actions.

The Julia Farr Association provided us with information and support and has published a paper on these service models.

We thank these organisations for their support. We will continue to work together with any organisation interested in developing these ideas further and we will continue to campaign for self managed care/individualised funding.

We firmly believe that it is important to give people with disabilities and their families and friends the opportunity to have a say over how such a system should be planned, managed and delivered. Without ownership by people with disabilities and their families and friends the system is set up to fail.

It is remarkable that once again South Australia is left behind as Western Australia, Tasmania, Victoria, New South Wales and Queensland already offer the option of individualised care packages.

1. Methodology

In March 2008 our organization attended the Community Forum organized by Arts Access SA as part of the Adelaide Arts Festival. Arts Access SA had invited the comedian Lawrence Clark to speak about self managed care, or individualized funding, or also called consumer directed care.

The South Australian Council of Social Services(SACOSS) had asked our organization whether we had any comments on developing such a service delivery system. We believed that it was crucially important to get the community of people with disabilities involved and to undertake a community consultation process.

We worked together with SACOSS, the Physical Disability Council of SA (PDCSA), the Northern Disability Forum, and the Regional Disability Forum in the Southern suburbs.

We consulted with the Julia Farr Association, which had not too long ago also held community consultations with Simon Duffy from the UK organization In-Control in attendance.

After a short introduction to the topic by Dr. Paul Collier, who has lived in the UK with individualized funding and is a person with a disability, and the video of Lawrence Clark from the UK, who was speaking on the topic, we asked the attendants of the consultation to ask as many questions as they could think of about the individualized funding/ self managed care system.

Overall attendees asked more than 60 questions, which we grouped into four areas:

1. Preparation for the delivery of individualized funding
2. eligibility and assessment, or access to individualized funding
3. Service delivery and protection from abuse of the service delivery system
4. Assessment and evaluation of service delivery

After each question session we divided the questions into themes and the attendees into small groups and gave each group between four to five questions to ponder and find workable solutions to the problems posed.

2. Outcomes

2.1 Principles of the self managed care system

Attendants at the community consultations identified several principles which all believed had to be in place in order to deliver a fair and equitable service to all people with disabilities.

The following principles emerged in all consultations:

- Entitlement to services for all people with disabilities
- A fair, simple, and equitable assessment of need for services
- Services need to be flexible and transferrable to all States and Territories in Australia
- Maximum self determination and choice for service users
- Maximum protection from abuse of the service delivery system
- Accountability of all parties: government, service deliverers, service brokers, and service users

2.2 Pre-requisites for a self managed care system

The participants voiced the need to develop protocols which would establish a self managed care system for the delivery of services needed by families and/or people with disabilities.

All participants recognised a **need for legislative changes to ensure entitlements to care** for people with disabilities. This could be enshrined in a Bill of Rights, which guarantees access to services for people with a disability and their families, or entitlements could be enshrined through amendments to the Disability Services Act, or by introducing enforceable standards in the Human Rights and Equal Opportunity Act.

The development of a self managed care/individualised funding model must take place in consultation with focus groups and other consumer participation methods to ensure the program is going to meet the needs of people with disabilities and their families.

Before the new service model can be implemented a simpler and **functionality based needs assessment** must be developed.

Once the model is developed there should be a **public awareness program**, which would include training on how a person can manage their own funding and how the new system would affect people with disabilities and their families. A campaign highlighting the change process for agencies and the relevant departments must also be developed about how a consumer driven service would change service delivery.

The development of **Plain English communications and pictorial explanations** for people with limited capacities is essential if all are to benefit from this new service delivery system. The development of a training system, for mentors and/or family members of people with limited capacities who want to manage their own funding, is also essential.

Self managed funding must be made available to all people with disabilities in rural and city areas.

2.3 Access to self managed care

The attendants expressed very clear opinions of who should be eligible for self managed care. A concern of the participants was that by changing to self managed care the government could restrict people's access to care, leading to the loss of the support/funding that people with disabilities are currently receiving. It was important to the community that people who are eligible for care now should be eligible for self managed care in the future and that they should not lose any of the support/funding they are currently receiving.

The participants thought that it should be an individual's choice to manage their own funds and not a decision of a government department. Some families may perceive the idea of managing their own funds as an additional burden whilst for other individuals it may be perceived as being an empowering way to control their own lives and a step towards improving their quality of life.

The community thought that trialing the system was a waste of time and that the new service delivery model should be based on the model in the UK so that time and money is not wasted in trialing a service system that already works.

2.4 Service delivery systems

2.4.1 "One Stop Shops"

The participants of the consultations believed that they needed a place/call centre/ website that would offer all the information needed to make well founded decisions in regard to managing their own or another person's support services. They did not want to have to chase answers to the questions that may arise in the process of accessing and managing services.

The use of an easy accessible website and a 1800 (freecall) phone centre would assist the community to access relevant information and would limit the stress of engaging with brokers and service providers.

These 'One Stop Shops' could be provided by Disability SA, and could also provide brokerage of services for those who want to remain in the old system.

2.4.2 What kind of services should be available through the new service delivery model?

The kinds of services attendants of the consultations wanted to be provided through self managed care were **all the services a person needs.** A short list provided below gives some detail of the services people identified during the consultations as services that should be accessible through self managed care/individualised funding:

- In home care
- Access to transport
- Assistance needed to access education, training and employment
- Leisure activities
- Day Care options
- Respite services
- Equipment
- Access to health and hygiene services (cleaning, incontinence pads, support with medical appointments etc).

The person receiving individualised funding should receive the funding from all the sources currently providing funding. Individualised funding recipients should have the right to control how this money is spent on any of these services and should have the right to choose which of the services they use and whom they employ to deliver the service.

2.4.3 Training

Training for people managing their own funding **should be provided for free**. TAFE courses could be delivered free to people assisting people with disabilities to manage their own funding and to service providers' personnel on how to maintain accountability.

Training for people with disabilities and their families should include:

- The kind of assistance and services available;
- How to train staff that people are employing;
- Budgeting, simple accounting measures;
- Insurance needed;
- Legal obligations of accountability and of employing personnel;
- Recruitment procedures, including interviewing skills;
- Assertiveness training;
- How to assist a person with limited capacities to choose their services.

Participants recommended that training should be provided through peer mentors, financial advisors/managers, and other experienced professionals.

It was also important to the participants that independent services should be established to ensure and guarantee independent brokerage and advice. Participants identified the need that such services should exist to prevent conflict of interest.

Participants also recommended that independent advocacy services, such as the Disability Advocacy and Complaints Service of South Australia Inc., should be resourced to act as independent watchdogs and that they should be prepared to intervene whenever an injustice has occurred or a person with a disability or their family/supporters have a complaint or grievance about a service provider.

2.4.4 A flexible system appropriate to the persons needs

A flexible progressive approach to service delivery is needed to cater for changes in a person's life and for unforeseen circumstances people may experience.

Service providers may need to be prepared to take over management of service provision if a person becomes ill or their health deteriorates suddenly. When a person is no longer able to, or does no longer want to control their own funds, family members or a Circle of Support should be introduced and trained to assist the person and manage their funding for them.

The **Circle of Supporters** should support and protect the rights of people with disabilities when they may no longer be able to do so themselves. The Community Living Project has already laid the foundations for the development of these Circles. They should be provided with extra resources to develop their model further to include the planning and management of individualised funding for a person with a disability (see http://www.clp-sa.org.au/).

Another important service would be the establishment of so-called **'Micro Boards'**, incorporated associations or Boards of Management, which act as financial managers for people with disabilities where the Circle of Support members feel that it is inappropriate to manage a person's financial affairs and at the same time provide support to manage their life.

These networks would need to be established at the beginning of an individualised funding service model to ensure that the whole spectrum of independence in individualised funding can be catered for.

A regular review system of a person's needs should be established in order to accommodate for a persons changing needs. Early planning and intervention planning are an essential part of a quality service delivery. Life changes such as the move from education to employment or day activities should be planned early and be foreseen in the care planning.

When ageing parents or caregivers are no longer able to care for their family member with a disability, the person should be able access a "circle of friends/supporters", an unpaid support network or a citizen advocate, as a safety net.

The spectrum of individualised funding has on one end the person who is fully capable and desires to completely manage all aspects of their life, at the other end of the spectrum is the person who is incapable of making and communicating any decisions.

The following table provides an idea of how participants saw the provision of services increasing in correlation with increasing incapacity of the person with a disability who has no close relatives who can assist them:

Level of Capacity	**Funding Management**	**Service Management**
Completely independent	Self or family members	Self or family members
Independent, but wishes to abdicate some responsibilities	Peer Mentor Assistance or Financial Service	Peer Mentor Assistance or Service Broker
Independent but needs some assistance	Peer Mentor Assistance or Financial Service or Micro Boards	Peer Mentor Assistance and/or Circle of Supporters or Service Broker
Can make choices but is unable to manage	Peer Mentor Assistance and Micro Boards or Government Department	Peer Mentor Assistance and Circle of Supporters or Peer Mentor and Government Department
Completely unable to make any choices	Micro Board or Government Department	Circle of Supporters and Public Advocate

2.4.5 Abuse prevention and accountability measures

Abuse prevention was seen as a very important measure for the participants in the consultations. One suggestion was to have a mandatory reporting line, so that people are able to call in and report if someone was abusing the funds of a person with a disability, or if service providers seem to abuse the system in any way.

The participants believed that service providers should be monitored and made accountable about the provision and charges for their services. It was important for the participants that independent services should provide brokerage. Participants indentified that such services should exist to prevent conflict of interest, that mission statements of such services must include fairness and equity, as well as clearly spelling out what is expected of all parties.

Independent watchdogs like the Disability Advocacy groups should be prepared to intervene whenever an injustice has occurred or is happening, and maybe should include in their briefs a kind of monitoring function of services.

Participants believed that people with disabilities and their families/supporters must also be held accountable and that the use of fortnightly electronic transferred funds and their expenditure shown on the account statements would provide enough evidence of how the funding was spent. Any kind of accountability system for the person with a disability and/or their families and supporters should be easy to maintain and be simple in its structure. Otherwise the ability of people to manage their own funding will be limited.

Congregated care settings should be monitored by an Official Visitors Program, which already exists in all other States and has been demanded for many years.

2.4.6 Evaluation of program delivery

Any kind of program and service ought to be reviewed/evaluated on a regular basis.

Self Managed Care/ Individualised Funding projects should be reviewed after 12 months by a pre-established board of professionals, consumers and advocates.

After 12 months an independent assessment panel, consisting of consumers and service providers, should assess the support and evaluate the success/failure of self managed support projects. Participants recommended that the evaluation should be based on previously agreed outcomes of the program, agreed values, and should include the level of satisfaction of the person with a disability who benefitted from the program. The evaluation should be conducted by independent assessors.

Participants expressed very clearly that the current practice of having no independent evaluation of any programs is a great short coming of current service providers. All programs and services ought to be regularly, and people with disabilities should be trained as assessors and play a dominant role in the evaluation of services. There should be an evaluation of existing programs as soon as possible in particular as the need for services is huge and growing and in view of the problems many people experience with their services.

3. Where to from here?

Participants believed that more talk fests would not lead to any better outcomes. Everyone was very clear that they wanted to implement Individualised Funding/Self Managed Care as soon as possible.

Most participants believed that there have been enough consultations and the next steps should be the establishment of a working group, consisting of interested stakeholders including people with disabilities and their family members, which has the following tasks:

- Development and campaigning for a change to legislation to include entitlements to services for people with disabilities;
- Development of ethical structures to support people with disabilities and their family members to access self managed care/individualized funding projects;
- Development and establishment of an independent information and assistance providing organization which assists people with disabilities and their families to dream and make choices and identifies service providers who are able to respond to those;
- Development of adequate and empowering training for individuals with disabilities, supporters, service providers and other stakeholders to enable access for all those who wish to participate;
- Development and establishment of safeguards;
- Establishment of a clearing house with best practice examples.

Once the initial thinking has been done and some of the elements for a successful system change have been developed and established, service providers will also have been able to plan for the new system of service provision.

Some service providers, such as Community Support Incorporated and the Community Living Project, have already begun to deliver self managed care models. They should be encouraged and enabled to continue with their projects. Others may need to rethink their service delivery models and retrain their staff to become true partners of people with disabilities.

The participants of the consultations expressed the hope that the disability community would be able to come and work together with government, bureaucracy and service providers to bring about the long desired change.

Participants expressed their sincere hope that the promises our previous Minister for Disability Services made are not empty promises but will be taken up by the new Minister and her Department.

Addendum:

One of the authors of this paper attended a workshop organized by the Department of Families and Communities of South Australia, the Better Practice Group and the Aged Care and Housing organization.

Dr. Michael Kendrick talked for two days about the strengths, pitfalls and necessary elements of self managed care/individualized funding.

His insights as a former Administrator and Public Servant in America and Canada, where he introduced self managed care were invaluable. He is currently reviewing and assessing many international projects.

We believe that South Australia would greatly benefit from having Dr. Michael Kendrick as a **Thinker in Residence** in this State. He would not only assist the State Government in planning for this change, he could train change managers and enlighten the wider community about what is possible.

For more information on his work go to www.kendrickconsulting.org

The Julia Farr Association has worked on the development of individualized funding and has a discussion forum and other papers on their web site. Go to www.juliafarr.org.au

Appendix: Articles on the Julia Farr Website discussing Self Managed Care/ Individualised Funding Options

Individualised Funding

Angus Buchanan(2006) The Predictors of Empowerment (152 KB)

Buchanan 2002 (or later) - Predictors of Empowerment (220 KB)

Cialdini R (1998) Influence ; The pscyhology of persuasion (53 KB)

Commission for social care inspections (2004) Direct Payments (841 KB)

Conroy et al (2002) Outcomes on self determination (965 KB)

Davis K (2004) Will consumer directed health care improve system (205 KB)

Disability Rights Commission (25 KB)

Doty et al - Consumer-Directed Models of Personal Care Lessons from Medicaid.mht (105 KB)

Dowson S and Salisbury B (1999) Individualised Funding: Emerging Policy Issues (141 KB)

Dowson S and Salisbury B (ed) 2000) Foundations for freedom (58 KB)

Fisher 2006 - Self-managed care (20 KB)

Florida Department of Elder Affairs - Consumer summary - Directed Care.mht (76 KB)

Frogue J (2003) The future of Medicaid Consumer Directed Long term care (177 KB)

Geron SM (200) The Quality of Consumer Directed long term care (95 KB)

http___www.in-control.org.pdf (106 KB)

Individualised Funding Information Resources (43 KB)

Kendrick 2001 - The Limits and Vulnerability of Indiviudalised Support Arrangeme... (60 KB)

Laragy 2002 - Individualised Funding in Disability Services (139 KB)

Lord and Hutchison 2003 - Individualised Support and Funding (118 KB)

Lord J,Kemp K & Dingwall C (2006) Moving towards citizenship.pdf (161 KB)

Marlett 2006 - Brokerage and direct payments (122 KB)

National Council for Disability findings.doc (66 KB)

Nerney & Shumway 1996 - Beyond Managed Care (45 KB)

Nova Scotia Dept of Health - Self_Managed_Care_Policy_Dec05.pdf (134 KB)

Nova Scotia Dept of Health Self managed care client guide (84 KB)

OAAAA - example of US Consumer_Directed_Care - oaaaa ohio Choices pgm.pdf (79 KB)

Phillips B & Schneider B (2004) Cangin to consumer directed care (484 KB)

Polivka L & Salmon J (2001) Consumer directed care.pdf (379 KB)

Salisbury 2000 - report on first conference (141 KB)

UN Enable - Text of the Convention on the Rights of Persons with Disabilities.mh... (138 KB)

Waterman, R Peters, T. and Phillips, JR (1980) Structure is not organsiation.mht (81 KB)

Williams R (2006) Individualised Care Packages - Forum - Link Magazine (1,822 KB)

Williams R (2007) Individualised Funding - An overview (189 KB)