Australian Federation of Disability Organisations

submission to the

Senate Community Affairs Committee

Inquiry into the funding and operation of the

Commonwealth State/Territory Disability Agreement

1.0 The Australian Federation of Disability Organisations

The Australian Federation of Disability Organisations (AFDO) is the peak national body representing organisations of people with disability. Our mission is to champion the rights of people with disability in Australia.

Our current membership includes:

National Members
- Australian Association of the Deaf
- Australian Mental Health Consumer Network
- Blind Citizens Australia
- Brain Injury Australia
- Deafness Forum Limited
- National Association of People Living with HIV/Aids
- National Council on Intellectual Disability
- National Ethnic Disability Alliance
- Physical Disability Council of Australia
- Women with Disabilities Australia

State Members
- Access for All Alliance Hervey Bay
- Disability Resources Centre

2.0 Summary of Recommendations

Recommendation 1

The CSTDA structures and processes should be urgently amended:
- To reflect a whole of government, whole of life approach to the delivery of services to people with disability.
- To intimately include people with disability in its development and monitoring, with a key role in setting the aim of the Agreement, nominating the priority issues to be addressed through it, and identifying the best outcome measures for assessing its effectiveness.
- To clearly allocate responsibility for overseeing the implementation of the Agreement to a single agency, with that agency given the requisite authority to perform this task.
- To provide for regular independent monitoring of the Agreement's effectiveness.

Recommendation 2

That the priorities contained in the next CSTDA be set in cooperation with people with disability. These priorities should be based on qualitative and quantitative evidence.

Recommendation 3

That research conducted under the auspice of the CSTDA more closely align with the performance outcomes contained in the Agreement.

Recommendation 4

That CSTDA research priorities be identified in cooperation with people with disability.

Recommendation 5

That Commonwealth, State and Territory governments develop population based planning tools to estimate future demand for generic and disability specific services by people with disability. These tools should be compatible with equivalent existing tools, such as that used for Home and Community Care services.

Recommendation 6

That the next CSTDA consider accommodation for people with disability in broad terms, recognising that this goes further than housing and incorporates support and assistance.

Recommendation 7

That work commence on the development of a Disability Standard for Accommodation under the *Disability Discrimination Act* (Cth) and that this be linked to the work of the CSTDA.

Recommendation 8

That models of services delivery that give people with disability decision making control be introduced. Accountability and reporting requirements in these models should be outcome focussed.

Recommendation 9

That the implementation of these models should be independently assessed against agreed outcomes and related performance indicators.

Recommendation 10

That the next CSTDA focus on supporting people with disability to make effective transitions such as from education/training and work and from work into retirement. This should acknowledge that people with disability are also parents and carers whose support needs will change as they transition in and out of the workforce.

Recommendation 11

That the next CSTDA give greater weight to primary intervention at the individual and systemic levels.

Recommendation 12

That the next CSTDA:
- include more provisions that exploit governments' positions as major purchasers and contractors.
- ensure that all research projects undertaken under the auspice of the CSTDA use a whole of government framework.
- reference major government commitments such as the Commonwealth Disability Strategy.

Recommendation 13

That the next CSTDA identify sustainable ways of meeting the increasing costs of accommodations to support communication access, including sign interpreters, Easy English and Braille, large print and accessible electronic formats.

3.0 Inquiry

The terms of reference for the Senate inquiry are:
   a) an examination of the intent and effect of the three CSTDAs to date;
   b) the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;
   c) an examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency; and
   d) an examination of alternative funding, jurisdiction and administrative arrangements, including relevant examples from overseas.

4.0 Introduction

Commonwealth, State and Territory Governments … seek to work cooperatively to build inclusive communities where people with disabilities, their families and carers are valued and are equal participants in all aspects of life.

(Preamble, 3rd CSTDA)

The current Commonwealth-State/Territory Disability Agreement (CSTDA), quoted above, is the third such agreement.

The purpose of the CSTDAs has been to establish areas of responsibility for service delivery and funding for the State and Commonwealth governments respectively, to identify priority areas requiring reform, and to identify opportunities for joint action.

Successive CSTDAs have had admirable aims, such as *to build inclusive communities*. However these have been undermined by the Agreements' focus on crisis management. Rather than steady progress towards a shared vision of the realisation of the citizenship rights of people with disability, Agreements have been haphazard and piecemeal, focussed on a relatively small group of people with disability with very high support needs, to the exclusion of the broader population of people with disability. Agreements have been reactive, not proactive, and people with disability have been excluded from the Agreements' development. As a consequence, opportunities for substantive structural reform and improvements in the quality of life of people with disability have been missed.

The current Agreement expires in 2007 and negotiations on the next agreement have commenced. These negotiations occur in the context of

anticipated increases in levels of demand for services, substantial existing levels of unmet need for services and continued demand for increased flexibility and responsiveness of disability supports.

At the broader policy level, the Commonwealth Government is reviewing its Commonwealth Disability Strategy and is an active player in the development of an International Convention on the rights of people with disability. The Council of Australian Governments (COAG) has also recently agreed to major reform of the way that the Commonwealth and State governments fund service delivery under the New National Reform Agenda (NRA). The NRA is based on equitable cost sharing, investment in early intervention initiatives and innovative approaches to service delivery (COAG 2006). In addition to the NRA, COAG has identified improved mental health services and accommodation options for young people living in residential aged care as priority issues.

This submission identifies ways that the CSTDA can be reformed to ensure that it is respectful of and relevant to people with disability, and to realise its potential to be a legitimate and robust planning tool. Recommendations in this submission focus on:

➢ improved coordination of policy and service provision across government;

➢ increased focus on improving the accessibility of generic services and community resources;

➢ improved accountability mechanisms;

➢ enhanced fit between the needs of people with disability and the provision of disability specific and generic services; and,

➢ the introduction of service delivery models which promote the realisation of the human rights of people with disability.

5.0 Assessing the effectiveness of the CSTDAs

> *… people with disabilities have rights equal with other members of the Australian community, and should be enabled to exercise their rights or be accorded these rights.*

> (Preamble, 3rd CSTDA)

The first Commonwealth State Disability Agreement aimed to clarify governments' respective responsibilities in the area of disability service provision. The second Agreement retained the core element of allocated

responsibilities and additionally allowed the Commonwealth to work with individual States on issues of relevance to each jurisdiction. The particular focus of the second Agreement was on improved public accountability and service quality (Ohlin 1999: 2).

The current (third) CSTDA identifies five priority policy areas:
1. strengthen access to generic services for people with disabilities;
2. strengthen across government linkages;
3. strengthen individuals, families and carers;
4. improve long-term strategies to respond to and manage demand for specialist disability services;
5. improve accountability, performance reporting and quality.

5.1 The effectiveness of the CSTDA as a strategic tool

The goal of the next and subsequent CSTDAs should be to enable people with disability to be full citizens. In this context, the CSTDA would form part of an intricate web of services and agreements, interacting with the Commonwealth Disability Strategy, other Commonwealth-State/Territory agreements, such as those in housing and health, and with human rights mechanisms and tools such as the Human Rights and Equal Opportunity Commission and the Standards developed under the *Disability Discrimination Act* (Cth). By providing a coordinating framework for diverse initiatives, the CSTDA would enable effective responses to be developed to complex issues, such as the overrepresentation of people with disability in the criminal justice system. It would also play an integral role in assisting Australia to implement and report against the International Convention on the rights of people with disability.

Unfortunately, the CSTDA is far from being a coordinated, high level strategic policy document. Despite its broad aim and the priority placed on access to generic services, the current CSTDA retains a narrow focus on service delivery, particularly disability-specific services, to people with disability aged under 65 years. The CSTDA is crisis driven, with the result that short-term, individually focussed interventions are prioritised over systemic reforms. For example, the provision of accommodation support services dominates expenditure under the CSTDA. In 2003/2004, more than half of the $3.28 billion spent by all governments under the CSTDA was used to fund accommodation support, as Chart 1 (overleaf) demonstrates.

This expenditure supported 33,175 people. At the same time, people with disability and people who are ageing have been denied the opportunity to remain living in their homes because they cannot access minimal funding support to modify their homes (install ramps and handrails etc) and because the introduction of minimum standards for housing visitability have not been prioritsed.

Chart 1: CSTDA Expenditure by Service Type 2003-04
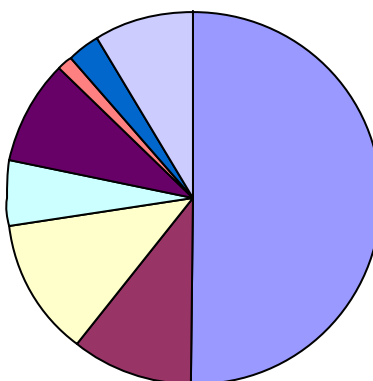
Legend:
- Accommodation
- Community support
- Community access
- Respite
- Employment
- Advocacy, information and print disability
- Other
- Administration

Source: AIHW 2005, Table 3.3

5.2 The effectiveness of the CSTDA on the ground

The assessment by people with disability of the effectiveness of the CSTDA is not positive. AFDO members advise that people with disability find navigating the services system exhausting and frustrating. People are not offered flexible service and support options and are required to coordinate support from a range of different services.   People with disability report:
- poor information about service availability, including a general lack of clear and accessible information about services;
- variations in the standard of services across States/Territories;
- a lack of coordination with local governments as service providers;
- poor access to services for people living in rural and remote areas; and,
- buck passing between levels of government.

Other major challenges identified by people with disability which impact on the effectiveness of the CSTDA:

o Maintaining the viability of essential services targeted at small population groups

   People with communication needs as a result of vision or hearing impairment or cognitive or intellectual impairment are finding it increasingly difficult to access generic and disability specific services which can accommodate their communication needs.

o Reduced availability of individual advocacy services

Many disability service agencies which have traditionally provided individual advocacy services have ceased providing these services, placing increasing pressure on remaining services.

o Poor capacity of providers of generic service to recognise invisible impairments such as mental illness and brain injury and to respond to the needs of people with multiple impairments

People with acquired brain injury, cognitive impairment, mental illness and dual diagnosis continue to receive inappropriate servicing as a result of their conditions being undetected. These groups are over-represented within the criminal justice system and the Centrelink payment reduction regime.

o Continued reliance on indicators of medical rather than functional impairment

Programs continue to categorise people on the basis of medical diagnosis, rather than functional limitation. This leads to inaccurate assessment of relative need.

5.3 Improving Assessment

The dissonance between the stated aims of the CSTDA and its practical implementation makes it difficult to assess its performance. The Australian National Audit Office performance audit of the administration of the CSTDA concluded "there are currently no adequate measures of whether, or to what extent, the CSTDA is meeting its objectives" (ANAO 2005: 3).

The CSTDA should be outcomes driven, with an assessment model that reflects this. Commonwealth and State/Territory governments have adopted this approach in the Council of Australian Governments mental health initiatives. A range of performance outcomes have been agreed to, with a select number of performance indicators chosen to measure progress against each outcome.

The assessment model and criteria developed for the CSTDA should have the potential to interface effectively with the monitoring mechanisms that will need to be established for the International Convention on the rights of people with disability.

A major barrier to the effective oversight of progress towards the achievement of the aim of the CSTDA has been that no single agency has been given the task and authority to do this. At a Commonwealth level alone, direct services to people with disability are provided by at least seven departments and most of

these are not involved in the Agreement. This makes it an impossible task for the Department of Families, Community Services and Indigenous Affairs, which is no longer the dominant agency in relation to disability services, to fulfil its responsibility to monitor the Agreement.

Independent monitoring of the effectiveness of the CSTDA is essential.

5.3.1   Recommendation 1
The CSTDA structures and processes should be urgently amended:
- To reflect a whole of government, whole of life approach to the delivery of services to people with disability.
- To intimately include people with disability in its development and monitoring, with a key role in setting the aim of the Agreement, nominating the priority issues to be addressed through it, and identifying the best outcome measures for assessing its effectiveness.
- To clearly allocate responsibility for overseeing the implementation of the Agreement to a single agency, with that agency given the requisite authority to perform this task.
- To provide for regular independent monitoring of the Agreement's effectiveness.

6.0   Assessing and measuring need

6.1 Assessing need
There is a tension between the need to address access issues systemically, while still retaining a focus on individual service provision. We must also find a balance between interventions aimed at the primary and tertiary levels. Arguably the current CSTDA is too weighted to individualised interventions at the tertiary end.

People with disability have criticised the poor match between the priorities for assistance identified by people with disability and the type of services that are provided. The 2003 Survey of Disability, Ageing and Carers identified daily living activities for which people with disability required assistance and the extent to which this need for assistance was met (Australian Bureau of Statistics 2003). Two of the three areas of need for assistance that have the greatest level of unmet need are transport and health care (see Attachment A for a full list of unmet needs).

Transport and health care are issues that are most successfully addressed through systemic accessibility initiatives such as disability standards under the *Disability Discrimination Act* (Cth). However, this is not provided for in the CSTDA or its associated research program, nor does the CSTDA link to existing initiatives such as the *Disability Standards for Accessible Public Transport*. This restricts the relevance and power of the CSTDA as a

strategic planning document. It also means that assessments of governments' progress towards achieving inclusive communities are likely to be underestimates.

In addition to transport and health care, people with disability have identified the following items are priorities:
- accessible housing and public environments;
- improved open labour market employment opportunities;
- effective and sustainable methods of providing communication assistance;
- improved support to obtain aids and equipment; and,
- enhanced financial assistance to support the participation of people with disability.

It is critical that the CSTDA aims, objectives and priorities be developed based on robust qualitative and quantitative evidence. The national minimum data set for disability services and the 2006 Census, which included questions on disability for the first time, offer the potential for improved population based planning in the future. In the meantime, data such as that provided by the ABS Survey of Disability, Ageing and Carers and information collected by organisations of people with disability provide the most effective basis for identifying the priority needs that should be included in the next CSTDA.

6.1.1   Recommendation 2

That the priorities contained in the next CSTDA be set in cooperation with people with disability. These priorities should be based on qualitative and quantitative evidence.

6.2 Measuring need

Were the priorities in the next CSTDA made more relevant to the expressed needs of people with disability, we would have limited measures for assessing the extent of met and unmet need for them and few benchmarks with which to assess the effectiveness of government interventions to address them. For example, we currently have no reliable estimates of the proportion of public buildings or private dwellings which are accessible to people with disability.   We have poor data about the employment experience of people with disability. We have almost no longitudinal data about people with disability.

People with disability are excluded from many of the fora in which research priorities are set, such as the National Disability Administrators, with the result that projects do not reflect the needs of people with disability and are less useful than they might otherwise be.

6.2.1 Recommendation 3

That research conducted under the auspice of the CSTDA more closely align with the performance outcomes contained in the Agreement.

6.2.2 Recommendation 4

That CSTDA research priorities be identified in cooperation with people with disability.

6.3 Unmet need for disability services

The current CSTDA focuses on:
- disability employment services;
- accommodation support services;
- community support services (such as attendant care and therapy);
- community access services (such as day programs);
- advocacy, information and print disability; and,
- respite services.

There is substantial current unmet need for services in these areas and this is predicted to increase as the result of demographic changes (AIHW 2002: 214). State and Territory governments do not keep waiting lists for many of these services, making it impossible to accurately measure unmet need or to effectively plan for future service delivery. The Australian Institute of Health and Welfare has estimated the level of unmet need for CSTDA services and this is outlined in Table 1.

Table 1: Estimated unmet need for CSTDA services, 2001

Service Type	Estimate of unmet need
Accommodation support and respite	12,500 people
Community access	8,200 places
Employment	5,400-6,000 people

Source: Table 7.1, AIHW 2002, Unmet need for disability services

The high level of unmet need and the likely growth in demand for disability services require governments to commit to substantial increases in disability funding and to the redesign of generic services and community resources. The latter is addressed in section 6.

6.3.1 Recommendation 5

That Commonwealth, State and Territory governments develop population based planning tools to estimate future demand for generic and disability specific services by people with disability. These tools should be compatible with equivalent existing tools, such as that used for Home and Community Care services.

6.4 Unmet need for accommodation support

The issue of appropriate living options for people with disability is complex and encompasses:

- the need to improve the accessibility of private homes to enable more people to remain in their homes when they acquire a disability;
- working with people with disability being cared for by elderly parents (or carers) and their families to identify sustainable care options into the future; and,
- identifying sustainable and dignified accommodation options for young people currently residing in residential aged care centres.

This should be a priority in the next CSTDA. It is important that work in this area does not get derailed into becoming a debate about buildings, bricks and mortar. We should keep sight of the primary issue: the effective provision of support and assistance to allow people with disability to choose where and how they live.

An effective way to frame this work would be through the development of a Disability Standard for Accommodation.

6.4.1 Recommendation 6

That the next CSTDA consider accommodation for people with disability in broad terms, recognising that this goes further than housing and incorporates support and assistance.

6.4.2 Recommendation 7

That work commence on the development of a Disability Standard for Accommodation under the *Disability Discrimination Act* (Cth) and that this be linked to the work of the CSTDA.

7.0 Alternative funding and service options

The Australian Federation of Disability Organisations and its members want reform of disability and generic services to achieve:

- people with disability having control over their needs and services;

- a whole of government and whole of life approach to improving the lives of people with disability; and,

- the meaningful inclusion of people with disability in discussions at all levels about issues and matters that impact on their lives.

7.1 People with disability taking control of their lives

People with disability have the right to determine their own needs and to make their own choices about how they would like to live their lives. However they are restricted by inflexible service delivery and funding arrangements that dictate which services they may have, when they may have them and who may deliver them.

Current service delivery models:
- are inflexible and unnecessarily restrictive in what is defined as a legitimate support service;
- do not allow people with disability to take risks, make mistakes or simply to change their minds;
- physically restrict people through the lack of portability of funding; and
- take decision making power away from people with disability and put it in the hands of service providers or carers.

(See Laragy 2002 and Disability Services Queensland 2003)

One response to these inadequacies has been the individualised funding movement. Internationally, the move towards individualised funding started in the 1970s in Canada and the United States of America. Programs to introduce individualised funding commenced in Australia only relatively recently (Laragy 2002). The Disability Services Commission in Western Australia currently offers a Combined Application Process through which an individual can access funding from three possible sources through a single application point (Disability Services Commission 2006). In recent years Victoria has trialled several models of providing individualised service funding, with varying success.

The individualised funding movement is arguably misnamed because the core issue is not money, but decision making control. People with disability must be freed to make their own decisions and the CSTDA should support this. A question to be considered by governments and the community is the extent and form of accountability that will be required from people with disability in relation to the use of public funding. Like the CSTDA, accountability by people with disability should be outcome focussed, in line with the goal of improving the quality of life of people with disability and enabling them to enjoy full citizenship.

The experience of individualised funding projects overseas, and to a lesser extent in Australia, offer some valuable lessons in the establishment of such projects. Laragy (2002) has identified:
- individualised funding systems are not simple and can be more complex for individuals and their families to navigate;
- people with disability should be able to choose the level of self-sufficiency they need and are comfortable with;

- individualising funding does not by itself lead to a person having increased control over their life or to a better quality of life - brokers can simply replace case managers as controlling forces;
- the removal of professional and service staff can lead to people with disability becoming increasingly isolated and more vulnerable to exploitation by family members and carers; and
- governments tend to abrogate their responsibility for individual support and service development once payments are devolved.

Research has also identified the risk that people with disability, their carers and families, who are often already under immense pressure, can be asked to take on even greater responsibility under individualised funding models. Not only do they become directly responsible for the results of poor decision making, research suggests that apparent cost savings and efficiencies in the model may be gained at the literal expense of individuals and families, who absorb the cost of managerial tasks that were once undertaken by others (Laragy and Frawley 2005).

Other important issues that need to be addressed as we move to an individualised funding model are:
- assisting people with disability and their families to identify and source services that may not be provided by existing disability service models;
- managing conflict of interest in models where disability service providers are also able to take on a 'brokerage' role; and,
- ensuring that people with disability are not asked to meet costs that should be born by other agencies.

The *in Control* program in the United Kingdom provides an example of a recent attempt to introduce individualised funding. The in Control publication "Frequently Asked Questions about in Control and Self-Directed Support" (attached at B) directly addresses important and contentious issues such as the potential for exploitation, obtaining genuine consent, and the role of families (in Control 2006).

7.1.1 Recommendation 8

That models of services delivery that give people with disability decision making control be introduced. Accountability and reporting requirements in these models should be outcome focussed.

7.1.2 Recommendation 9

That the implementation of these models should be independently assessed against agreed outcomes and related performance indicators.

7.2 A whole of government/whole of life approach to reform

It is essential that individualised funding and reform of the disability services system is counterbalanced by a whole of government commitment to achieving universal accessibility. While this was included in the current CSTDA, it was inappropriately placed as an item under policy priority 1. A whole of government commitment should provide the framework for the operation of the entire CSTDA.

The CSTDA should also refocus on primary interventions, that is, early intervention. Early intervention can occur at the individual and systemic levels. For example, increasing access to hearing aids can lead to the reduced incidence and severity of dementia (Peters, Polter and Scholer, 1988). Investment in the effective implementation of the *DDA Standards for Education* will improve future labour force participation rates.

7.2.1   Recommendation 10

That the next CSTDA focus on supporting people with disability to make effective transitions such as from education/training and work and from work into retirement. This should acknowledge that people with disability are also parents and carers whose support needs will change as they transition in and out of the workforce.

7.2.2   Recommendation 11

That the next CSTDA give greater weight to primary intervention at the individual and systemic levels.

7.2.3   Recommendation 12

That the next CSTDA:
- include more provisions that exploit governments' positions as major purchasers and contractors.
- ensure that all research projects undertaken under the auspice of the CSTDA use a whole of government framework.
- reference major government commitments such as the Commonwealth Disability Strategy.

7.3 Meaningful inclusion of people with disability

People with disability should be partners in all discussions about issues that affect their lives. This requires proactive support that acknowledges that people communicate in a range of ways.

7.3.1   Recommendation 13

That the next CSTDA identify sustainable ways of meeting the increasing costs of accommodations to support communication access, including sign interpreters, Easy English and Braille, large print and accessible electronic formats.

8.0 References

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Unmet Need for Assistance with Activities of Daily Living, 2003

Activity for which assistance is required	% unmet need - profound limitation	% unmet need - severe limitation	% unmet need - moderate limitation	% unmet need – mild limitation	% unmet need – all with limitation	Number of people with unmet need
Self care	7	12	-	-	10	52,960
Mobility	4	8	-	-	6	48,630
Communication	3	3	-	-	3	6,198
Cognition or emotion	3	4	11	8	6	45,096
Health care	5	4	7	11	6	57,198
Paperwork	4	3	10	6	5	19,050
Transport	5	5	13	19	8	68,680
Housework	2	4	8	10	5	45,470
Property maintenance	3	3	7	9	6	72,810
Meal preparation	3	1	1	4	2	6,220

Source: 2003 Survey of Ageing, Disability and Carers, ABS, Table 14

(NB that the formatting of this document has been altered, but not the content)

Frequently Asked Questions about In Control and Self-Directed Support

Authors: Carl Poll, Simon Duffy (with some answers being provided by participants at local In Control meetings).

Questions below are grouped under these headings:

- Self-Directed Support
- Direct payments
- Money
- Risk
- Support
- Support brokers
- Individualised services
- Issues in the local authority

If you have questions and don't find answers here you can go to our 'Contacts' page.

PERSON-CENTRED PLANNING

Isn't this just Person-Centred Planning by another name?
In Control's model certainly incorporates Person-Centred Planning (PCP) into the process. PCP is the basis for In Control's Support Plan. Helen Sanderson Associates are partners in the programme and are helping to ensure that PCP is at the heart of it.

But, it is evident that if a person has a plan, but they don't have control of their funding and support, and if social care is commissioned and provided as it is now, then that person is unlikely to really be in control of their life.

DIRECT PAYMENTS

Isn't this just Direct Payments by another name?
Direct Payments are one important option for making funding individual. In Control's model includes Direct Payments, but it goes much further.

In Control is developing a system that will work for everyone. Everyone should be able to get self-directed support, even if they don't want to manage a Direct Payment. There are other forms of individual funding available including Indirect Payments, funding held by trusts, and Individual Service Funds. Even people who want their support purchased by their care

manager should be receiving support that has been designed to fit them and their life – this is self-directed support.

What's the difference between In Control and Direct Payments?

The In Control model is quite clear in placing Direct Payments as one of a number of payment methods within the overall system.

The resource allocation system – the heart of In Control and Self-Directed Support – is obviously independent of Direct Payments. Nonetheless, the question continues to be asked

In some places (West Sussex, for example), local initiative in getting the best out of Direct Payments has expanded their responsiveness to individuals. In other places, it's more difficult to see how they can be confused.

So what's the difference?

- DPs are an important mechanism for people controlling their support money. But they aren't the only one – Indirect Payment, Trust, Individual Service Fund (and the Care Manager holding the money for a few) – are the others. DPs don't suit everyone.
- However, DPs remain a very strong tool in the hands of people with disabilities, and, though we rightly emphasise the other payment options, being seen as the person with the cash grants status.
- In Control offers a whole system – with policies and procedures for resource allocation, support planning, supported decision making etc.
- DPs currently operate outside of a system of Self-Directed Support – they are not dependent on there being a resource allocation system like In Control's.
- So DPs in themselves, don't offer any transparency or equity in the allocation of funds to individuals – they generally come at the end of the care planning process, one in which the individual may have little presence. In some places at least the care management process may allocate money unfairly, unequally, or quirkily. Certainly, the rules and assumptions about the status of the individual are very different and far from In Control's principle of entitlement to a share of the community purse.
- However, DPs, viewed from the perspective of someone about to get one, are completely in tune with In Control's resource allocation system – that person just wants to know how much they are going to get.
- DPs within In Control's model can be so much more powerful, because they are a payment method for an amount which has been known since the first stage – assessment and resource allocation.
- Most DPs are used to buy support from Personal Assistants. Though this can be valuable, we emphasise that natural and informal supports are critical in a support mix which enables people to play a full role as equal citizens.

MONEY

Where's the money going to come from to pay for Self-Directed Support?
There is no new money for Self-Directed Support. If Self-Directed Support could only happen when large amounts of new funding become available, it is unlikely that it would happen at all. So, the money will come from that which social services are already spending on social care. However, this approach should also help people identify and use other sources of funding (e.g. the Independent Living Fund, Benefits, Employment, Community Services, Health, Education and grants).

But what if the money's not there?
In Control maintains that, overall, it is possible for people to direct their own support without new monies being found. Experience in Scotland, the US and elsewhere (see the stories page) show that, for the amounts of money people would have got anyway, they can create supports which suit them better.

Is this really just a way to do things on the cheap?
Self-Directed Support isn't cheaper, but it can be more creative and make better use of the money available, so that someone gets more for their money.

How accountable will I be for the use of the money?
You will be accountable. The Support Plan and the Support Contract together say what you agree to do with the money – they form a contract. Any big changes must be agreed with the local authority.

We know about Direct Payments. But are there other ways that someone can have control of their money?
Yes – someone you trust can look after the money for you. Or you can have a Trust – a group of people who have a set of rules for looking after the money. Or an organisation you trust can keep your money in a special account just for you and give you support that is just for you.

In all of these, you should have the real control (with help, if you need it).

What if someone can't open a bank account for their funding?
Under the Disability Discrimination Act it is illegal for banks to refuse to open an account for someone because they have a disability. However, someone must be able to understand what the account is for. If they can't, someone else – a representative or a trust – can open the account or they can have a joint account.

Will it affect benefits?
Receiving money for support does not affect benefits.

If someone works, how does this affect their funding for Self-Directed Support?

The money you get for support is the same if you are working or not working.

If there are extra costs in the transition process, will there be extra funding?
Someone might need more funding at the beginning and the Council will take this into account when saying how much money someone can have.

RISK

How can we make sure the person understands what's involved in Self-Directed Support and that decisions are made which are the person's?
There is an In Control policy on Supported Decision Making which sets out how to make sure of this. You can get this on this website on the policies page.

How can we be sure that someone is consenting to participate?
There are guidelines in the In Control Policy on Supported Decision Making. A Supported Decision Making Agreement should be made between the person, any representative and the Council based on the principles in the Policy.

Aren't individual services open to abuse?
Disabled people may be at extra risk of abuse. But, there is no reason to think that Self-Directed Support is less safe than living in hostels, group homes or other services. Self-Directed Support should be organised to minimise the risk of abuse by:

- Putting the person in control of their life
- Making sure people who love the person are enabled to stay in touch
- Designing an agreed system of support and safeguards that fit that person's preferred lifestyle

Being known to many people in a local community can be the best safeguard for vulnerable people.

In Control has a Health and Safety Policy (available on this website) which answers many questions about risk of abuse.

Might families abuse the finances – or the person? For example, what happens when families absorb the person's benefits into the family income and won't release it for the persons own use?
A Supported Decision Making Agreement (see the policies page on this website) will say if the person has a representative and who that is. The Policy on Supported Decision Making (also on this website) sets out clear principles about who should represent someone and how they should be represented. The approach recommended in these documents should prevent such cases of abuse, but the actions of the representative must be monitored.

The local authority must ensure that the Agreement and the person's circumstances are regularly reviewed. Ideally, the person will have a Circle of Support or an advocate.

From experience to date, there is little evidence that families representing someone in directing their support will abuse their position. Indeed, in most cases, family members show great integrity and care.

FAMILIES

What happens if someone's family won't support them in their wishes and plans?
The person who wants to be in control is the most important person. If the family won't help, then the Council can arrange for that person to get other help – perhaps from a support broker.

How does this all fit in with the carer's assessment?
A Carers' impact assessment is part of the assessment to determine eligibility and level of funding that someone will get.

In Control seems to take family support for granted. That doesn't seem right.
In Control is an attempt to change the system as it exists. Family support isn't paid for in the current system of care. If In Control said we should count in family support 100% - effectively pay for all of it – it would, as a national system (or even at a local authority level), break the bank and mean that the move to Self-Directed Support would never get support from local authorities.

What if a family isn't capable of playing a leading role?
It will, of course, be good if all agree that a family member can represent someone and hold a bank account - if that's what they want and need. But there are other ways that people can get this support – through support brokers or circles of support, for example. For a small number of people the Care Manager may still be the best person to take the lead.

When it comes to managing the funds, there are a number of other ways of dealing with this – a Trust can be set up, a trusted organisation can hold an Individual Service Fund, or the Care Manager can hold the funds.

What about on-going support in training for families?
Local authorities will need to be creative in fostering supports for families through, for example, mentoring arrangements or mutual support networks. Families may also be able to benefit from training which Social Services is organising anyway.

What will happen if the family can't play a lead role anymore?
The local authority will need to provide someone who can play this role or provide support which will enable the family to continue.

We haven't got the admin back-up to do it.
There shouldn't be too much admin to manage the support. Where services like payroll and legal advice are needed, the costs of these can be written into the Support Plan.

SUPPORT

If it all goes wrong, what happens? Where does the person go? Will they keep the benefits money?
There is no guarantee that any kind of support will work for someone. This is no different with Self-Directed Support. But, there is a lot of flexibility with Self-Directed Support, so you can make big changes. If having this kind of control really doesn't suit someone, they can use the ordinary council arrangements of care planning and commissioning.

What will happen to people remaining in grouped services?
If people want to leave existing grouped services then this will create a real challenge for Councils. Local authorities will need to put in place plans to help this shift towards individual funding.

In recent years the trend has all been in this direction and it seems likely that people will continue to choose more individual forms of support as they get the chance to do Person Centred Plans. However if people want to pool their individual funding to purchase support together then this is fine too – as long as it is based on what people really want to do with their funding.

What happens if I change my mind?
You can always go back to having the Council organise your support for you.

What happens if I want to live with someone who lives in a different council area?
This is hard to answer – it depends on where the other person lives. Different councils say different things. Councils are waiting for the Department of Health to tell them what should happen. However, if that is what you want to do, your Council will talk to the other Council and see what they have to say.

SUPPORT BROKERS
Where is support brokerage on the national agenda?
The Government's Green Paper on Adult Social Care explores various roles which could help people to plan and organise their support. A number of possible terms are floated – 'care navigator', 'care manager' etc. In Control strongly believes that 'support broker' is the best term at the moment to capture the role.

What is support brokerage?

- A broker can't be someone who commissions or provides services

- Someone might work for a provider agency and be a broker so long as the brokerage function is somehow put at arm's length from the provider's other interests – we want to encourage providers to consider how to do this.
- Not everyone needs a broker – some will plan and implement the plan themselves. Others will need help. But this shouldn't automatically be provided by professional brokers – family, friends, or a circle of support can provide this support, too.
- 'Isn't it just good care management?' is often asked. Care managers can't be brokers as such. But, in a menu of options for people getting support to plan and implement their support plan, care managers might still, for some people, be the best placed to help
- 'Support broker' is the best title we've come up with after much consultation. The Green Paper's 'care navigator' or even 'community matrons providing care management' are titles which, in themselves, carry meaning and will determine, I think, an unhelpful direction in the development of support.
- Brokers must add value. Not everyone needs one, and the usefulness of brokers will be decided in the marketplace in which people controlling their own support budgets are the customers. If local or national systems are created in which everyone has to have a broker, much public money which could be given to people for their support, will be wasted.
- There is no single way to do brokerage, and we know relatively little about it. So, authorities should exercise caution when thinking of setting up a brokerage project – a project will offer something to some individuals but not others. Flexibility and responsiveness to the requirements of individuals should be the watchwords. In practice, this should mean that local authorities should beware of putting all their eggs in one basket. Instead, they would do well to encourage a variety of arrangements – perhaps some independent brokers alongside any agencies set up for the purpose, and brokers who specialize in e.g. housing.
- There is an increasing body of knowledge through the In Control pilots (especially Essex) and this is being disseminated through the brokerage network facilitated by Alison Short at In Control.

How can we be sure that service brokerage will genuinely serve the person's interests?
The best way is to see if the person gets support which is individual to them and which is better than that they would have got through the ordinary care planning and commissioning method.

How can I get support brokerage?
Support brokers are people who help to plan and organise support. There aren't many support brokers in England yet. But a number of councils are starting to build up support brokerage arrangements. You need to tell Social Services you want a support broker.

HOUSING

What housing is available? Where will it be? Is it local? Who will provide it?

Availability of housing is a national problem and there's no special housing arrangement for people directing their own support. The sources of housing are social housing lets – Council and housing association - ownership and shared ownership, and private renting. In each of these, there are some creative things which can be done.

Councils need to be as creative as possible in developing these options. Families and supporters can also help. A useful website about getting the best out of a difficult housing market is www.housingoptions.org.uk.

INDIVIDUAL SERVICES

Doesn't this mean we'll have to close all the day centres?

If people can choose the life they want and do not choose day centres, this may, indeed, mean that day services will have to change radically. But this is required by Valuing People anyway. All local authorities will have strategies to manage this change.

One of the principles of In Control is that people get the same kind of consumer power that anyone has when choosing where to spend their money. This inevitably means that those providing services must pay attention to what people are willing to buy.

Aren't individual services socially isolating?

There is no reason that this should be the case. Directing your own support means that you can get closer to a life that is right for you. Usually this will mean wider not narrower networks.

How can organisations respond? What will they do if Self-Directed Support is really how all social care is organised?

Organisations need to look at how they can change what they do to suit a more 'customer-driven market'. What will people need? For a start they will need support brokers, help with payroll, legal advice, and help to recruit workers who are individual to the person, support to get involved in communities.

Aren't individual services too expensive?

There are lots of precedents which show how people can have individual support at no extra cost. People can, with the help they need, usually get greater value from the money that would have been spent on traditional services.

What's the difference between Self-Directed Support and Supported Living?

There are some things which are the same about both – in supported living and Self-Directed Support you should have control over who supports you. You should have control over the important decisions about your life.

But supported living is about living in your own place with the support you need.

Self-Directed Support is having control over the money for your support. And it's about having control of your support.

In supported living you will always have your own place to live. But you may not have control of the money for support – the Council might still buy in the support.

In Self-Directed Support, you could be living at home with your family.

ISSUES IN THE LOCAL AUTHORITY

If we do this, will families constantly challenge our assessment?
The Resource Allocation System is designed make entitlements to funding clear and open.

How do we monitor/safeguard? How will we know people are safe?
There will be a contract and Support Plan and Care Managers will need to review how well the Plan is working – how much the person is being supported to reach their objectives set out in the plan.

The close involvement of family, friends, local people, circles of support or support brokers will also be important in ensuring that someone is safe day-to-day.

Will there be enough social workers to do the assessments?
Yes because the assessment for funding is not complicated and won't usually take long.

What will happen to care managers? Will they have a role?
Care managers are usually overstretched and often don't have the time to spend on the important detail in individual cases. Self-Directed Support should allow care managers to spend time on the people who have the most complex support needs. They will also have an important role in ensuring good resource allocation, checking that people produce good plans, monitoring and reviewing.

How does the Resource Allocation System work?
Councils start by examining how they spend their money at the moment. People with particular needs tend to get certain levels of funding spent on them. These levels are used to make a resource allocation system. Care Managers look at the circumstances and needs of a person and decide quickly what level of funding the person is entitled to. The person can then go off and plan knowing how much money they have. If, when they've produced a costed plan, it becomes clear that they need a different level of funding, they can discuss this with the social worker. (See the papers on resource allocation on this website).

Will we have a legal challenge because it's inequitable?
The allocation of funding isn't inequitable. In Control is simply a way of telling people openly about what they are entitled to - and the Resource Allocation levels are based on what people get anyway.

In Control is not challenging the Fair Access to Care guidelines, and there is no basis for a legal challenge.

Care Managers have to meet ISO standards. Could family involvement compromise these standards?
There's no reason to think family involvement would produce outcomes which are not as good as those achieved at present. The achievement of outcomes set out in the Support Plan will be clear evidence of good 'performance'.

We can't change all our policies to allow this to happen.
The six local authorities which are participating in the pilot of In Control are working through policy issues which arise from using Self-Directed Support. So far, all indications are that it is perfectly possible to bring local policies into line with the policy framework proposed by In Control. You can see the policies which Wigan has developed on this website.

What level of compromise is acceptable in making the finances of a support package/RAS work?
The Resource Allocation System in each local authority will follow current patterns of spending. This means that the levels allocated through the RAS will fit the circumstances of most people. However, when the support planning process reveals that the level allocated really doesn't fit the person's circumstances, it is possible to review the allocation.