Office of the
Public Advocate

South Australia

Submission to the

Productivity Commission

Inquiry into
Disability Care and Support

August 2010

The Public Advocate
is an independent official accountable to the
South Australian Parliament

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1 Executive Summary

1. Our submission addresses the application of UN CRPD and, in particular, Article 12. This promotes equal recognition before the law and access to the support required for decision making. It is an important breakthrough in advancing self-determination and equality of rights for people with disabilities. Dignity, individual autonomy and freedom to make ones own choices and a focus on 'persons' and their 'personhood' are essential principles for any new scheme and important principles for any form of individualised funding.

2. The requirement for support to make decisions has led to an international focus on the development of supported decision making systems – no person should have another person appointed to make a decision on their behalf, if they could make the decision themselves with assistance and support.

3. In Australia there has been considerable investment in guardianship services, but no similar systemic investment in decision support services. As a consequence, persons who might otherwise be able to make a decision themselves (with communications assistance or personal support) may have a guardian appointed because of the absence of an organised supported decision making system.

4. South Australia's Office of the Public Advocate has described a stepped model of supported decision making and support prior to formal guardianship. This illustrates how the system can be rebalanced towards interventions that might be less intrusive and deliver better outcomes.

5. South Australia is also investigating whether supported decision making can be an effective alternative to substitute decision making and provide wider benefits. The Supported Decision Making (SDM) Research Trial will assist people develop relationships with supporters, provide education to the parties about supported decision making and help establish a supported decision making plan that will guide parties in providing and receiving support.

6. While the SA SDM trial is based in the Office of the Public Advocate, supported decision making belongs in the community. In the future assistance to set up agreements, and to provide advice

and further help to participants when required, does not need to sit with a state official. If there is legislative backing such work could instead be undertaken by the non-government sector along a model used in British Columbia. As Australia inevitably moves towards supported decision making in line with the UN Convention it is likely that jurisdictions will develop statutory supported decision making regimes.

7.   If decision support services are provided in the non-government sector the question of funding arises. The two options would be to fund them either as part of the guardianship sector or as part of the disability sector.

8.   Arguably decision support is no different to other areas of personal support, so should be a support and rehabilitation function of the disability sector. An NGO that provides assistance with a supported decision agreement to an individual should not be the same NGO that provides other direct services because of the possibility of conflict of interest – as many of the decisions that will need to be made will be about services and accommodation.

9.   The UN Enable office has suggested that resources could be moved from guardianship to supported decision making.[1] However guardianship services have at the current time been facing an increasing demand from aged care, usually to provide substitute decision making for people with advanced dementia. We would expect therefore that it would be difficult to reduce guardian numbers to pay for supported decision making, as these guardians will still be needed to respond to the escalating needs of our ageing population, even if the need for guardianship for people who have a disability will be less than it might otherwise have been because of the availability of decision support.

10. Small NGOs in each state, with expertise in supported decision making could assist people to set up supported decision making agreements. The funding of these organisations could be incorporated into any new disability insurance scheme. Because this type of work is periodic, involving some hours initially, but then usually episodic follow up assistance after that, the level of funding could be a small percentage of any individualised payment. It would be important that provision for this is built into the recipients funded support requirements.

11. It is timely and important to be re-thinking guardianship and decision making rights. The UN CRPD provides a focus for disability on justice, rights and self-determination. It places greater value on social inclusion and accessibility and identifies how to support people with a disability to exercise their rights.

12. There is an undeniable dichotomy between the concepts of guardianship and those of person-centred planning and self determination. SDM provides an opportunity to be very clear about what is being offered in the way of decision making support before opting for guardianship. In this respect, SDM can be both an important facilitator and tool; and a safeguard, for ensuring people with disabilities make their own plans and choices in life wherever possible.

13. Our submission makes the case for an investment in the types of structured supports required for SDM implementation and how these and the practice of SDM and these supports can deliver a sense of connectedness back to the community, belonging and participation, for people with a disability.

14. The link between the practice of SDM (and the possibility of reframed guardianship frameworks) and early intervention and prevention is discussed. People living with disability and their families will have more personal authority in their lives and more active inclusion in the life of the wider community; their capacity and confidence in doing so will develop as a result. The approach of providing 'support' rather than 'guardianship' has many positive benefits for the individual with a disability and their families.

15. Importantly, SDM re-defines how other people will think about capacity and through this, extends the opportunities for people with a disability. SDM encourages people to be more person centred in their dealings with people with a disability; through practising SDM, others will have the help and information on how to do this, make adjustments and respond to their choices and decisions. It will support others, including families and friends, to nurture self-determination and choice.

16. The development of policies and community attitudes that are accepting of a more liberal and extended approach to capacity will create and grow the opportunities for people with disabilities, to participate as citizens, consumers and service users in their own right.

17. The UN CRPD promotes self-determination as a human right. Self-determination is inextricably linked to thinking and practice of individualised funding. We explore the linkages between individualised funding and SDM and look at practices, research and findings in other jurisdictions, particularly Canada, a leader in the disability movement, and where SDM and individualised funding has been practised for some years.

18. A key finding was the need to ensure access to independent planning support. Support that helps people with disabilities, if they choose to use it, to develop a clear vision for their life; planning support that is accountable to them and their families, not funders (with potential interests to restrict costs) or providers (with potential interests to increase demand for their services); and support that envisions what is possible rather than available and what could be created rather than what is to be limited.

19. We found, and agree, that implementing individualized funding, requires a 'status and recognition' approach to self-determination, or else it can fail to bring about a real change in status for people with disabilities and their family members or in the power relationships in the system. Self-determination is not simply about a choice, or an individual skill, or consumer power. If a new disability scheme does only this, it will fail to grant respect, social and legal recognition to people with a disability.

20. Brokerage as a concept and model was explored, and we found considerable variation in its implementation and practice, and as a result, varying benefits. Careful consideration of the concept will be required especially as a proliferation of Independent Professional Brokers accompanied the move to personalisation of services and budgets in the UK.

21. Individual funding without enhancement of rights can be disempowering, nor can it of itself build inclusion. Funding is required for community development strategies to build inclusive communities and open up opportunities for people with disabilities to enjoy their rights and status. Educational, employment, recreational, housing and other sectors, need to better fulfil their human rights obligations to include and accommodate people with disabilities. They too need appropriate resources. An investment in the talents and gifts of people with disabilities and in the support that comes from family, friends, supporters and enduring relationships is needed, in addition to meeting their functional and personal care needs. Training and education in rights

needs to be more widely available, for people with disabilities, their families and the wider community.

22. The change program will need to engage with and address the various interests of people with disabilities, families, service providers, employees, unions and funders; to build a common ground of respect and recognition; and to keep the momentum moving and focussed on rights. People with disabilities should be central to this program and provided with leadership opportunities in it, and if needed, support and training to assist them fulfil these roles.

23. In conclusion our submission puts forward the strong view that;

   ▪ Supported Decision Making can be an integral component to the design of a national insurance scheme so that it operates within a human rights framework that promotes autonomy and self determination. For many people there is an inextricable link between decisions that they need to make about personal matters – and the choices that they need to make about services. A unified approach to decision support can work for all areas of personal decision making, and be an integral part to a system of individualised funding and personal disability insurance.

   ▪ There are significant gaps in our current systems to provide decision support at this time. If these gaps are not addressed there is a potential for the benefits of future individualised funding arrangements to be lost if people are not supported to make choices. Because of lack of support there is a risk that people might leave decisions for others to make, continue with the same decisions that others have made for them in the past, or allow brokers to make choices for them.

   ▪ For people who need SDM related supports, the proposed insurance scheme, could meet the relatively small cost of obtaining this from independent non-government organisation who have expertise in developing SDM Agreements and plans, and providing further back up to people involved in these decision making arrangements when required.
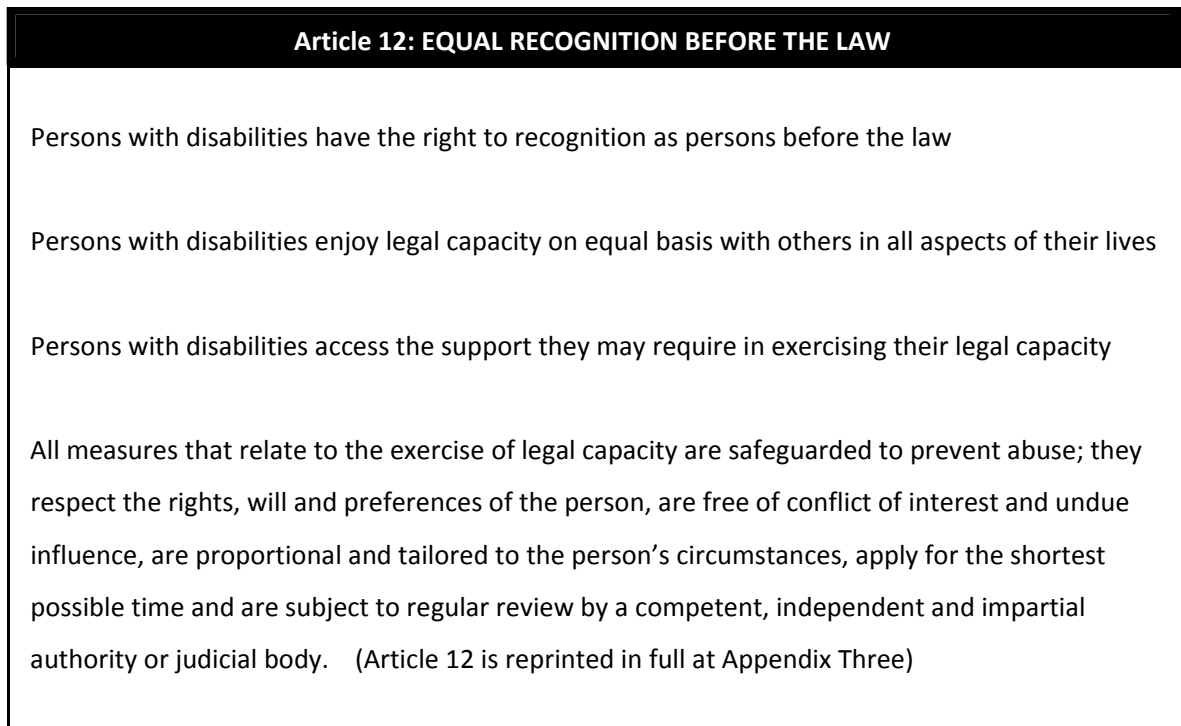
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2 Background

24. The Public Advocate is an independent statutory official accountable to the Parliament of South Australia. The Public Advocate is supported by an office. The Office of the Public Advocate (OPA) is funded by the Attorney-General's Department of the Government of South Australia.

25. General functions and powers are spelt out in Section 21 of the South Australian *Guardianship and Administration Act 1993* (*the Act*), and are reprinted in full at Appendix One. In summary, for mentally incapacitated persons, OPA should
    - keep under review all programmes designed to meet people's needs
    - identify unmet or inappropriately met needs and make recommendations to the Minister
    - promote rights and interests (for individuals and groups)
    - negotiate on behalf of individuals on issues arising from their incapacity
    - monitor and give advice on the exercise of powers and administration of this Act
    - perform other functions assigned to it under this or any other Act.

26. The latter point includes acting as the guardian of last resort, and undertaking investigations requested by South Australia's Guardianship Board (GB).

27. Private guardians can be appointed by an Enduring Power of Guardianship (EPG) but when these do not exist, an application for an order can be made to the Guardianship Board (GB), which may then appoint a family member, friend or the Public Advocate. The GB can also request an investigation by OPA.

28. OPA currently has 20 staff and each year provides active guardianship services to approximately 600 South Australians. A guardianship order can be for up to 3 years at which time it must be reviewed and if no longer required, revoked. As of March 2010 the GB estimates that it has appointed 167 private guardians since July 2009. The number of people acting under an EPG is unknown.

29. The Act requires guardians to follow set principles. The Public Advocate, however, has proposed amending the Act to add new principles about presumption of capacity, the decision-specific

nature of capacity, and the need to provide all possible assistance to people to make their own decisions. The current principles and suggested changes are set out in Appendix Two. These additional principles were put forward in OPA's 2008-2009 Annual Report in order to promote discussion between interested persons and agencies.

30. The proposed changes reflect international thinking about Guardianship and Administration. Such thinking has been both a response to and also an influence on Article 12 of the United Nations Convention of the Rights of Disabled Persons (UN CRPD) [2.] See Figure 1 below.

Figure 1

Article 12: EQUAL RECOGNITION BEFORE THE LAW
Persons with disabilities have the right to recognition as persons before the law
Persons with disabilities enjoy legal capacity on equal basis with others in all aspects of their lives
Persons with disabilities access the support they may require in exercising their legal capacity
All measures that relate to the exercise of legal capacity are safeguarded to prevent abuse; they respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest possible time and are subject to regular review by a competent, independent and impartial authority or judicial body. (Article 12 is reprinted in full at Appendix Three)

31. The Secretariat for the UN CRPD cites British Columbia, Canada as an example of good practice in supported decision making. There a person can enter into a "representation" agreement with a network of supporters who can assist with making decisions and provide representation when needed (UN Enable, 2008).[3] If there is evidence of a trusting relationship then such an agreement can be entered into without the need for a person proving their capacity.

32. In the United Kingdom (UK) a new Mental Capacity Act 2005[4] has as its starting point a clearly stated presumption of capacity and a right to autonomy - for adults - to make their own decisions. Innovations associated with this new UK Act and the development of supported decision making in

Canada are generally considered consistent with the UN CRPD principles and indicative of the direction future law reform and practice should take.
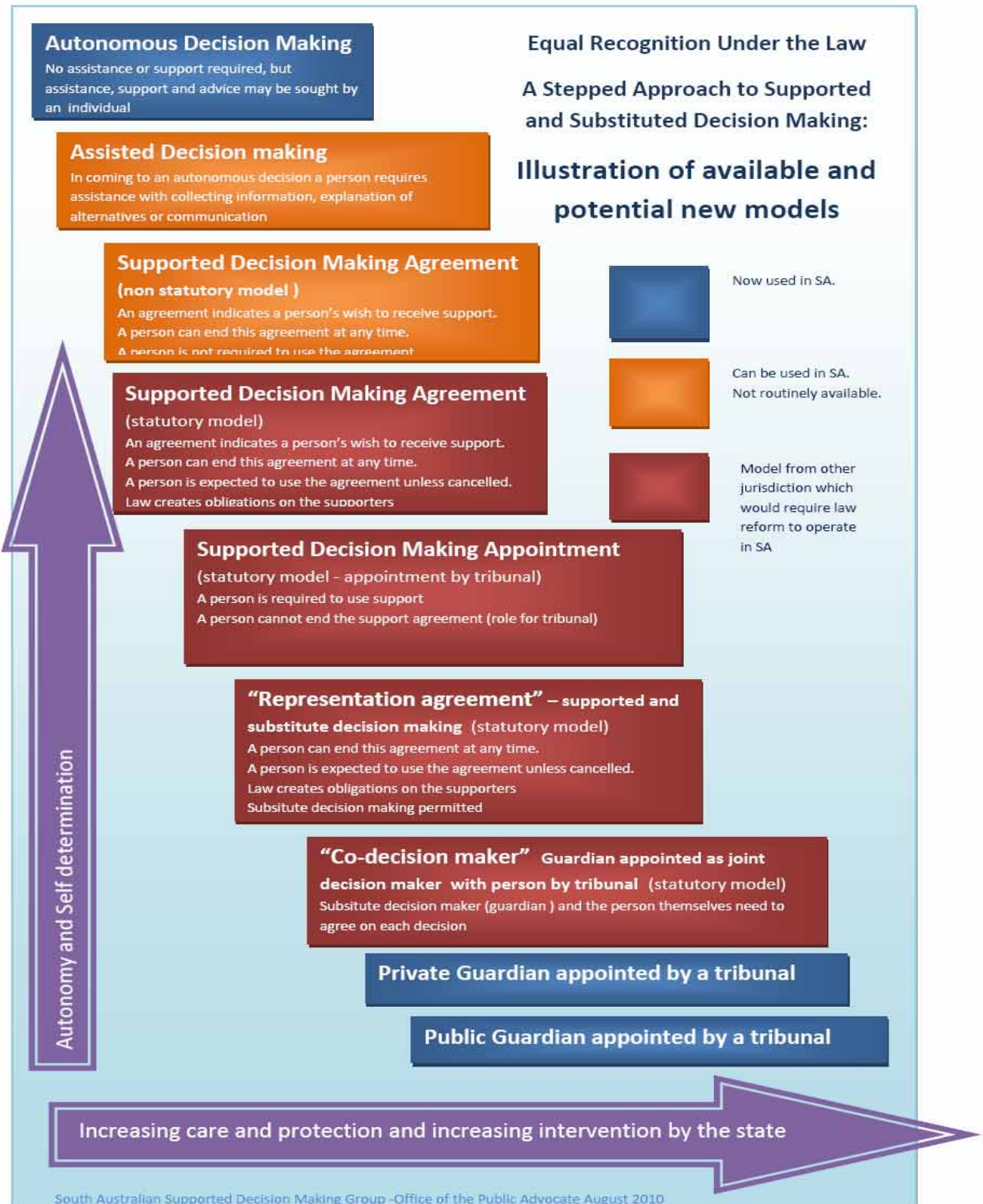
A stepped model of supported decision making and support

33. SA's Public Advocate has described a stepped model of supported decision making and support prior to formal guardianship. The continuum of possible approaches is illustrated in Figure 2.

34. In this stepped model the degree of autonomy and self determination for each intervention (supported decision making and guardianship) have been charted against the level of intervention by the state. A feature of stepped models is that if the system is unbalanced people will receive the more intensive, intrusive and usually more expensive intervention as opposed to the intervention that might be less intrusive and deliver better outcomes.

35. In Australia we have an unbalanced guardianship system. There has been considerable investment in guardianship services, however there has been no systemic investment in decision support services. A consequence of this is that persons who might otherwise be able to make a decision themselves (but require communications assistance or personal support to do this) may have a guardian appointment, because of the absence of an organised supported decision making system.

36. The stepped model describes possible levels of intervention. Definitions vary, but for the purpose of this model a distinction between assisted and supported decision making is made. *Assisted decision making* may require the use of communication assistance and decision making aids. This assistance could be provided by service providers, family, friends or other disability support organisations. For many people it may take time to carefully communicate information on more than one occasion. The assisted person is then able to make a decision. In *supported decision making* a person or persons are appointed to provide decision support. These people may be family, friends or any trusted others who become part of the conversation with providers and others when decisions are made.

37. The appointment of a supporter is usually by agreement. In a non-statutory model the agreement acts simply as a statement by a person that they wish another person to support them. In a statutory system there are greater obligations on all parties to use the agreement. Even when a

supported decision making agreement is defined by law, a key factor is that the person who is supported can end the agreement themselves at any time.

38. An alternative model of a tribunal appointing a supported decision maker, requires a person to use this support, and the appointment can only be cancelled by the tribunal rather than the person themselves.

39. The British Columbia "representational agreement" model, while aimed at providing supported decision making, also permits substitute decision making by the supporter when required.

40. SA has commenced a Supported Decision Making Research Trial to investigate the option outlined in paragraphs 36 and 37. Information about this trial is at page 12.

Figure 2 - A Stepped Approach to SDM

Autonomous Decision Making
No assistance or support required, but assistance, support and advice may be sought by an individual

Assisted Decision making
In coming to an autonomous decision a person requires assistance with collecting information, explanation of alternatives or communication

Supported Decision Making Agreement
(non statutory model)
An agreement indicates a person's wish to receive support.
A person can end this agreement at any time.
A person is not required to use the agreement

Supported Decision Making Agreement
(statutory model)
An agreement indicates a person's wish to receive support.
A person can end this agreement at any time.
A person is expected to use the agreement unless cancelled.
Law creates obligations on the supporters

Supported Decision Making Appointment
(statutory model – appointment by tribunal)
A person is required to use support
A person cannot end the support agreement (role for tribunal)

"Representation agreement" – supported and
substitute decision making (statutory model)
A person can end this agreement at any time.
A person is expected to use the agreement unless cancelled.
Law creates obligations on the supporters
Subsitute decision making permitted

"Co-decision maker" Guardian appointed as joint
decision maker with person by tribunal (statutory model)
Subsitute decision maker (guardian) and the person themselves need to agree on each decision

Private Guardian appointed by a tribunal

Public Guardian appointed by a tribunal

Autonomy and Self determination

Increasing care and protection and increasing intervention by the state

Equal Recognition Under the Law

A Stepped Approach to Supported and Substituted Decision Making:

Illustration of available and potential new models

Now used in SA.

Can be used in SA.
Not routinely available.

Model from other jurisdiction which would require law reform to operate in SA

South Australian Supported Decision Making Group -Office of the Public Advocate August 2010

Supported Decision Making Research Trial

41. This year, in collaboration with the Julia Farr Association and with financial support from the Julia Farr M S McLeod Benevolent Fund, OPA is commencing a two year trial of supported decision making. This trial will be formally evaluated.

42. The South Australian (SA) Supported Decision Making (SDM) Research Trial has been planned to have two parts; one will test SDM as an alternative to guardianship (for people who might otherwise be subject to guardianship if they cannot be seen to make decisions for themselves) and the other, will test SDM as an early intervention strategy for people not yet under guardianship. The latter is an exciting element that might prevent problems occurring in the future, avoid the need for guardianship orders and facilitate age appropriate responses and skills in self determination.

43. The project, will investigate whether SDM serves as an effective alternative to substitute decision making and beyond this, what are the wider possible benefits of SDM? One hypothesis is that SDM will at the very least provide an effective alternative to substituted decision making, enabling people to avoid loss of their legal rights and /or government intervention. A second hypothesis is that as an outcome of SDM people living with a disability will enjoy a range of other benefits related to community inclusion, and autonomy.

44. SDM has its origins in the disability field and related movements, particularly in Canada. Our project will draw on the work of an NGO in British Columbia [5] (NIDUS, formerly Representational Agreement Resource Centre), which was identified by the United Nations as best practice.

45. In SA the SDM Research Trial has been developed in the context of current legislation. While it is consistent with the aims and purpose of South Australia's *Guardianship and Administration Act 1993* and the role of the Public Advocate to assist people find alternatives to guardianship, current legislation does not establish a supported decision making regime. Therefore a non-statutory agreement model will be used.

46. The SA SDM Research Trial will assist people develop relationships with supporters, provide education to the parties about supported decision making, and help establish a supported decision

making plan which will give the parties strategies to follow in providing and receiving support. A person's wish to receive support will be recorded in an agreement.

47. For the purposes of our pilot the specific decisions identified in the Act which require GB approval will be excluded (i.e. selling property, prescribed treatment such as ECT or sterilization). For the project, SDM will not be offered nor promoted as an alternative to financial administration, although it is recognised that where it is linked to lifestyle and accommodation decisions, it indirectly becomes related to SDM practice. It should be noted that in several provinces in Canada, SDM is used for financial affairs, with appropriate safeguards.

48. In the SA SDM Research Trial each supported person will also nominate a "monitor", to assist with the process of supported decision making (rather than the making of actual decisions). The monitor will also take action if they consider that the supported decision making process is not working.

49. While this model is suitable for the research trial which will be closely monitored and evaluated, in the future if there is a widespread acceptance and use of SDM it will require specific legislation so that the role and purpose of SDM and the roles of each of the parties is clear to all. This has occurred in Canada, and in the UK principles requiring the use of support prior to appointing a guardian are in place.

50. Our submission addresses why supported decision making is important to any new disability scheme and funding arrangements and draws on the research undertaken for our SDM Research trial and the lessons from other jurisdictions.

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3 Why is Article 12 Important to the Inquiry?

51. The promised objectives and rationale for a new disability system have been clearly stated in the Productivity Commission's Issues Paper:

   '……………the overarching goal of Australian governments' disability policies is to enhance the quality of life and increase the economic and social participation of people with disabilities and their families, including enhancing and protecting their rights.' [6]

52. The Inquiry is about how a new disability scheme could be designed, administered, financed and funded. Clearly, the suitability and purview of different types of funding arrangements / programs must be related to the underlying objectives of policy.

53. The Issues Paper cited above also says that the above objectives are reflected in a range of related policy, regulatory and spending by governments, for example, on building and accessibility regulations, anti-discrimination and community education policies and programs.

54. Policies and practice in guardianship and decision making rights are also relevant to disability policy objectives. In particular, the UN CRPD provides an impetus to legitimise the practice of supported decision making. If so, this would greatly assist the Australian Government to achieve its overarching policy goals. Michael Bach [7] explains the importance of policy and program conditions (political, legal, service delivery and policy) to the implementation of funding arrangements, person centred planning and for self determination.

   'One of the most entrenched barriers to individualized funding and to self-determination more broadly is the legal distinction entrenched in law between the competent and incompetent. Rooted in 14th Century English statutory law, and reflected in various competency-related laws such as guardianship provisions, this legal distinction has been one of the major obstacles to people with intellectual disabilities obtaining control over their funding for disability-related supports. Capacity to enter service contracts and employ support providers is questioned, and often this status is denied solely on the basis of having an intellectual disability. Orders of supervision in institutions, formal guardianship orders, interpretations by Canada's tax department, Revenue Canada, liability and other requirements on physicians and financial institutions to ensure legal capacity to make decisions, have all conspired to deny decision-making status. Efforts to overcome these legal barriers have been promoted through work by various groups in Canada to develop a "supported decision-making model", as an alternative to guardianship.' [8]

55. Australia ratified the UNCRPD in July 2008 and assented to become a party to the Optional Protocol in August 2009. This commits states, agencies and service providers to make all *reasonable accommodations* in their dealings with people with disabilities so they can exercise their legal capacity. Reasonable accommodation is defined as

    '(the) necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.' [9]

56. The UN CRPD provides a focus for disability on justice, rights and self-determination. It places greater value on social inclusion and accessibility and identifies how to support people with a disability to exercise their rights.

57. Persons with disabilities and their families, however, spend much of their time simply surviving. The typical response is 'welfare" oriented, with an emphasis on maintaining rather than empowering persons with disabilities. A key message from the UN CRPD is that people with disabilities are to be regarded and respected, *first and foremost,* as citizens with equal rights, aspirations to live well, a capacity to contribute to the community and to make their own decisions.

58. The current system is built predominately around services (or lack of these) and often the regulation, policy and practice that are intended to support people with disabilities reflect a deficit view of them. As a consequence community capacity, the idea of 'people helping people' has been diminished by a focus on services and the problems, difficulties, incapacities and crises of persons with a disability. Add to this a culture of risk aversion or well meaning paternalism and an environment of inadequate resources and this problem is compounded. Under the current system providers, families and relatives have to present the person with a disability in the 'worst case' in order to attract the resources and services. Consequently, their gifts, talents, capacities and contributions are rarely seen or lauded - and even more rarely, funded or supported to further develop and enjoy.

59. In this context, re-thinking guardianship and decision making rights is timely and important. There is an undeniable dichotomy between the concepts of guardianship and those of person-centred planning and self determination. That is not to say that Australia's guardianship system overall is not already a good one. Tribunals are very cautious about appointing substitute decision makers

and have for a long time, sought to maintain informal arrangements and pursue the least restrictive option. However, the tenet of SDM is not to rely on nebulous informal arrangements, but to be very clear about what is being offered in the way of support. In this respect, SDM can be both an important facilitator, tool and a safeguard, for ensuring people with disabilities make their own plans and choices in life wherever possible.

60. Retaining rights should not mean that either people themselves or the community will be at a greater risk. The reasons for this are firstly, the decisions that are likely to work and fit best with the person, will be the ones that people make for themselves rather than ones made for them. Secondly, most failures to deliver services are because the system does not provide a service, rather than that services are refused. Thirdly, for some situations of severe or profound impairment when there is risk, Substitute Decision Making will still be required.

61. If the new disability strategy is to deliver the promises of person centred and personal outcomes planning, self determination, more power for people with disabilities (and their carers) to make their own decisions then it must empower _and_ assist the person with disability to make their own decisions. The system should be asset based, person centred and both promote and facilitate citizenship. Outlined in Figures 3 and 4 below are the principles identified for such a system in a 2000 Canadian review of their disability service system. [10]

Figure 4 - The Starting Point: What families and people with disabilities wanted

A NEW VISION FOR COMMUNITY LIVING … _a vision of choice and change…Preliminary_
Foundations for an environment of supports around people with disabilities and their families that sees individuals with a disability as full citizens of their communities,   ▪ honours and encourages their contributions,   ▪ places trust in the capacity of individuals and families to lead their own lives effectively …….. to meet the challenges they face ….. and to develop their own support system,   ▪ builds the strength of individuals and the resilience of families to move away from dependence on government services,   ▪ is built upon the premise of respecting the decisions of individuals and families,   ▪ builds capacity in communities that recognizes & values the contribution of people with disabilities, and,   ▪ provides support to individuals and families when they need that support.

Figure 5 - The Final Principles

A NEW VISION FOR COMMUNITY LIVING … *a vision of choice and change….Final*

The above principles guided the work from the outset. Others were added as the work to design a new approach progressed. The final principles guide an approach that that:

▪ Recognizes all people have gifts & contributions to make as citizens of their communities;

▪ Considers services as just one means by which people are supported to contribute as citizens;

▪ Shifts the focuses away from the supply of programs and services to more flexible supports as the primary response to adults, children and their families in need;

▪ Views adults, children and their families, along with friends and personal networks, as having the capacity to solve their own problems;

▪ Ensures that individuals and families have choice in terms of how they meet their unique challenges including the choice of Individualized Funding;

▪ Provides independent planning support to preserve the quality of choice;

▪ Welcomes the contributions of families and others in the system;

▪ Represents the highest and best use of public funds, with greater accountability and increased value for money spent;

▪ Reduces the amount of regulation and bureaucracy involved in the delivery of support to families and individuals; and

▪ Builds resilience in families & individuals reducing dependency on expensive government services;

▪ Encourages innovation and creativity;

▪ Moves from a "needs based" system to one that is capacity and asset-based;

▪ Sees community development as an economic stimulus and opportunity for communities;

▪ Is founded in relationships built on trust;

▪Makes a commitment to life-long support for both children and adults;

▪Builds on relationships and current capacity already in communities.

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62. While pre UN CRPD, the above proposed system of disability support, is similar to the convention's goals. Equally if reflects the desires and aspirations of many people with a disability and their family and support networks. Implicit in such a system is the need to provide adequate resources for the person with a disability and their families for personal planning and decision making

supports, and for the management and coordination of their own services and budgets if that is their choice.

63. The United Nations Secretariat has suggested that resources could be reallocated from guardianship to SDM. However, in Australia, we do not have structured decision support systems and existing guardianship services (which already operate under the principle of the least restrictive option) are over stretched and facing further pressure due to demographic change. There is a gap.

64. This support should be part of any new disability scheme and funding arrangement. While guardianship professionals will practice supported decision making, and in many cases already do, to relegate supported decision making supports to the guardianship jurisdiction is antithetical to self determination and the very legal rights that SDM seeks to maintain.

65. The next section of this submission will provide more information on SDM, the types of structured supports required for its implementation and how the practice of SDM and these supports can deliver a sense of connectedness back to the community, belonging and participation, for people with a disability.

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4 Supported Decision Making

66. Article 12 of UNCROPD promotes equal recognition before the law and supported decision making for people with disabilities. It states that an individual cannot lose his/her legal capacity to act simply because of a disability, but recognises that some people with disabilities will require assistance to exercise this capacity. Parties to the agreement commit to ensuring that this support is available and also to providing safeguards against abuse of this support.

67. Article 12 of UNCRPD is consistent with the Commonwealth *Disability Services Act 1986* [11] that regulates services for people with a disability generally and for those that the Commonwealth currently provides. The principles and objectives state that every person with a disability should have the chance to

    - develop fully his or her physical, social, emotional and intellectual abilities
    - use services which help him or her to achieve a reasonable quality of life
    - participate in decisions which affect his or her life
    - receive services in ways that result in the least possible restrictions of his or her life and opportunities
    - make a complaint about services he or she receives.

68. The *Disability Discrimination and Other Human Rights Legislation Amendment Bill* [12] was assented in July 2009. This Act makes it clear that employers, service-providers and governments have a positive duty to make reasonable adjustments in their practices or environments to take account of a person's impairment.

69. Some of the policy implications arising from Australia's signatory to the UN CRPD include; when should guardianship be invoked and how guardianship services should be delivered; what efforts must be made to avoid or limit the loss of legal rights even when traditional test(s) of capacity may not be fully met; and how to meet the expectation it creates that people will be given assistance to make their own decisions, with a guardian only appointed when this is not possible?

70. The impact of SDM though, is far wider than guardianship. It has the ability to transform how service providers, doctors, professionals and others, including family members, respond to people with disabilities and their wishes.

    '……….*what animates the entire UN CRPD is how **others behave towards you'** [13]

71. A recent Australian definition of SDM is

    (*SDM) is a framework within which a person with a disability can be assisted to make valid decisions. The key concepts are empowerment, choice and control. Responsibility, including legal responsibility, is another essential aspect that needs to be considered.*' [14]

72. There are several overarching benefits of SDM. Firstly, the amount of personal authority that people living with disability have in their lives will be increased by providing an alternative to guardianship and state interventions. Secondly, where family are informally assisting an individual it will place these arrangements on an firmer footing, based on agreements with the individual and their relative about what areas they can continue to represent the individual's decisions, rather than an assumption about an automatic right (of the family) that may occur at present. Thirdly, as a consequence of having an alternative to guardianship and if need be, agreements with family members or significant others, their legal and personal capacity to make decisions will be enhanced and respected.

73. The SDM agenda also links with key international movements to have individualised funding, person centred planning and to better connect people to their communities. With individualised funding, a person who has a disability makes their own decision about what services are purchased with the dollars the government provides. SDM provides the framework and ensures supports are available to assist individuals and families to use and manage individualized funding. This is discussed further in section seven of this submission.

74. With respect to community connection, it is about the creation of new social networks when existing networks do not exist — such as the circle of friends. People are visited, they have support, and these people might then be members of the group who are supporting decisions. Professionals still have a role in training and overseeing the establishment of support agreements.

75. The current systems of Substitute Decision Making is staffed by workers who are driven by rights, commitment to individual autonomy, and a wish to see that people get the help that they need. The need to move to supported decision making is not a critique on the good work of these professionals.

> *'No matter how well we do our jobs, how much we want to fight the good fight to help people retain independence and fulfil their goals, we are actors in a system with limited options [15].*

76. Without an established funded system of SDM, the only option might then be a Substitute Decision Making appointment. In current systems, appointed guardians often use SDM approaches. Yet, because of the very nature of the guardianship appointment, the final decision is seen as that of the guardian. The decision does not belong to the person themselves. If a form is to be signed, it will be the guardian who will sign off.

77. Similarly, if day-to-day services such as supported accommodation are limited, this may lead to a greater reliance on Substitute Decision Making. For example, people who have behavioural disturbances secondary to an intellectual disability can respond well if they are cared for in a calm, spacious environment, with sufficient care staff, and have psychological input - SDM will work well. The same person living in an unsuitable group home or institution that is busy, crammed, without enough staff, may not only be seen as requiring guardianship but could experience physical and chemical restraint and be detained in a setting that is not suitable.

78. Guardianship professionals work in a paradox as illustrated by this quote from Terry Carney [16] :

> *'At the heart of the jurisdiction in a contradiction: The ideology of freedom is linked to a set of legal tools to restrict freedom through the appointment of substitutes. Guardianship laws use a modern rhetoric of personal rights promoting autonomy, fostering independence, and assisting citizens to participate in social life. And yet the main task of guardianship forums is to strip citizens of rights, entrust proxies with the exercise of legal decision-making, and sometimes authorise incarceration through physical and chemical means. The strange paradox of using coercive forms to achieve emancipator purposes raises practical questions about what could possibly constitute successful intervention in this Alice in Wonderland world?' [17]*

79. This paradox is recognised, and valued. It is fortunate that guardianship work is done by people driven by the principles of autonomy and freedom. However, SDM is more in keeping with the rights focus of the jurisdiction.   There is no paradox.

80. The following slides explain supported decision making, the principles underpinning it and the framework for implementation in Canada and come from a presentation by Michael Bach.[18]

Slide 1

What is supported decision making?

● An accommodation in legally-regulated decision-making processes to protect the right to exercise self-determination for those vulnerable to losing this right

● Provides legal recognition and status to trusted others to assist in any aspect of protecting the personhood of an individual

– Decision-making

– Reflective capacity

– Personal identity – weaving narrative coherence

● Based on a 'narrative ethics' - A recognition that our bodies and selves are best made and exercised jointly with others in the context of a personal life plan

Slide 2

<div style="border:1px solid #000; padding:10px">

<div align="center">**Principles of Supported Decision Making**</div>

- All individuals of legal age are persons before the law and have a right to self-determination and respect for their autonomy, irrespective of disability

- All adults are entitled to the presumption of capacity [& identity], irrespective of disability, and to the decision-making supports necessary to exercise capacity and reveal identity

- Decisions [and identity] made interdependently with family, friends, and trusted others chosen by the individual, will be recognized and legally validated.

- All individuals have a will, and this will is capable of being interpreted and forming the basis for competent decision making [and identity].

- Individuals are entitled to the supports and services necessary for full participation and equality. The provision of such supports will lessen the need for legal intervention in decision making.

  Third party interests and liability concerns do not provide a valid justification for removing a person's decision-making rights.

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Slide 3

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<div align="center">**Montreal Declaration**[19]</div>

6a. People with intellectual disabilities have the same right as other people to make decisions about their own lives. Even people who have difficulty making choices, formulating decisions and communicating their preferences can make positive choices and decisions that further their personal development, relationships and participation in their communities.

6b. Consistent with the duty to accommodate in paragraph 5b, people with intellectual disabilities should be supported to make their choices and decisions, to communicate them and to have them respected. Accordingly, where individuals have difficulty making independent choices and decisions, laws and policies should promote and recognize supported decision-making. States should provide the services and the necessary support to facilitate persons with intellectual disabilities in making meaningful decisions about their own lives.

6c. Under no circumstances should an individual with an intellectual disability be considered completely incompetent to make decisions because of his or her disability. It is only under the most extraordinary of circumstances that the legal right of persons with intellectual disabilities to make their own decisions can be lawfully interrupted**.**

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5 Supports needed for exercising legal capacity

81. Article 12.3 requires support to be provided to people with disabilities to exercise their legal capacity. A systemic approach to support is required given the longstanding disadvantage people with disabilities face in having their right to legal capacity recognized, protected and promoted.

82. The broad requirements for supported decision making have many common elements:-

- A set of guiding principles that emphasise the persons' right to self-determination and autonomy, the presumption of capacity, and right to decision-making supports to enable equality before and under the law, without discrimination on the basis of disability.

- Recognition that a person's will and intent can form the basis of a competent decision-making process which does not remove person's decision-making rights.

- Recognition that decision-making assistance is often required by any individual - interpreter assistance, facilitated communication, assistive technologies, plain language etc and that legal and practice provisions validate their use in a supported decision making model.

- Valid decision-making assistance also includes the provision of any type of assistance to an individual in making a decision, expressing their will, or having others help them communicate their personal preferences and aspirations to third parties.

- People have access to independent planning support, if they choose it, that enables them to develop a clear vision for their life; planning support that is accountable to them and their families, not funders (with potential interests to restrict costs) or providers (with potential interests to increase demand for their services); planning support which envisages what is possible rather than available and what could be created rather than what is limited.

- Supported decision-making networks or representatives designated by the individual on the basis of trust and commitment to assist a person in making decisions, understanding their choices and the consequences and to help represent them in exercising legal capacity but without being substitute decision makers.

- Assisting other parties to understand the person, their life goals and identity, alternative communication needs and their duty to accommodate their expressions of will and intentions. SDM is also likely to take time - to communicate, to understand and to meet, perhaps, often.

- Working with others to facilitate support networks for people who are isolated or unable to identify a trusted person to assist them will also be important. For people in institutional settings, the focus might be ensuring that support is available to them that facilitates and respects their personal decision making.

83. Examples of the range of practical decision-making assistance that needs to be available (identified from literature and program reviews) include:-

   ☑ Informal assistance of family and friends in making daily decisions and carrying out activities of daily life including concepts such as circles of support or friends.

   ☑ Provision of individualised plain language assistance, assisted/adaptive communication, visual aids and other assisted communication technologies.

   ☑ Supported decision-making representatives/networks and assistance in developing and maintaining these representatives/networks so that individuals can designate those who are to represent and assist them in decision making, problem solving, mediation and monitoring.

   ☑ Support to other parties that are engaging in relations with people with a disability to help them understand how a person communicates and how they can meet their duty to provide reasonable accommodations.

   ☑ Practice guidelines would need to be developed and be readily accessible to all parties.

   ☑ Information, education and awareness campaigns about human rights, legal capacity, decision-making assistance, including supported decision-making networks.

   ☑ Advocacy support to individuals to exercise and protect their right to legal capacity.

   ☑ Community support systems that provide individualised, flexible and responsive disability related supports.

   ☑ Practical assistance to people with disability, their families and supporters to make SDM agreements and preferably, a register of such agreements (See Figure 6 below).

84. Nidus® is an example of the support provided for personal planning and SDM in BC, Canada. It is a non-government organisation that provides education and training about supported decision making, assists parties develop supported decision making agreements, provides advice to people about the operation of the agreements and for a fee maintains a register of agreements.

85. Ideally any legal framework for SDM would include protections from liability for supported decision-making representatives/networks and other parties in assisting a person in making decisions, and for entering agreements with an individual via supported decision making - provided such actions are done with a duty of care and not negligence. The British Columbia (BC) *Representation Agreement Act* [20] provides such protections.

86. Information about Nidus®, from the organisation's home page, is at Figure 6 below. This organisation has between 2 and 4 staff, and registers approximately 600 agreements per year and currently has 5000 registered agreements. It also has from time to time received once off grants for project work, development and education activities. The Public Guardian and Trustee of British Columbia [21] (PGT BC) has e-links to Nidus on its website and information about Representation Agreements.

Figure 6 - Information on Nidus from their Home Page

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Nidus:

☐ is a non-profit, charitable organization, incorporated in 1995 by community organizations and citizens involved in adult guardianship law reform.

☐ Established as a resource for informing and assisting the public with Representation Agreements and other personal planning tools.

Nidus provides:

☐ public legal education on personal planning tools/related legislation;
☐ training for volunteers and groups;
☐ problem-solving and coaching in support of best practices for
☐ attorneys, representatives and monitors; and
☐ policy consultation for third parties

Nidus also operates a centralized Registry for Representation Agreements and Enduring Powers of Attorney in partnership with Juricert Inc. of the Law Society of British Columbia.

Personal Planning

Personal planning is about making arrangements in case you need assistance with managing your financial affairs or making health and personal care decisions. A Will comes into effect only *after* your death, but what about situations where you need help now due to an accident, illness or disability?

In BC, if you are 19 years or older, no one has the automatic right to act on your behalf if you are found incapable. By making a legal plan, YOU choose who speaks for you.

Background

In 2000, BC adopted the Representation Agreement Act (RA Act), a new law designed to facilitate personal planning. The RA Act is the result of a grass-roots law reform initiative and offers a safe, flexible, and effective legal planning tool for:

Adults who need help with decision-making today & Adults who want to plan for their future.

The RA Act is the first legally-binding example of a supported decision-making model in the world. It helped inspire Article 12 of the UN CRPD, which champions equal recognition of legal capacity and the right to support with decision-making.

A RA Agreement, under the RA Act, is the only way in BC to appoint someone to act on your behalf for health and personal care matters (if you can not make an enduring Power of Guardian due to legal capacity tests). RAs can also cover routine financial and legal matters.

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6 Early intervention, prevention & capacity building

87. The promise of early intervention in SDM is an exciting element that might prevent problems occurring in the future, avoid the need for guardianship orders and facilitate age appropriate community responses to, and opportunities for, self determination and decision making.

88. SDM has the aim of increasing the amount of personal authority that people living with disability and their families have in their lives; increasing the person's active inclusion in the life of the wider community; and capacity-building, within the person, their family and the community.

89. Adults with a disability, when they come of age, and their parents are no longer in a legal position to make the decisions that they used to, will be able to consider and agree with their parents the areas that they want and need parental assistance with decisions. Parents will be able to continue to assist their son or daughter to make decisions without the need for guardianship.

90. Where family currently informally assist their son or daughter to make decisions, it will place these arrangements on a firmer footing; based on agreements between the individual with a disability and their parents, about what areas they can continue to represent their decisions or where their preference is for somebody else to be the decision making supporter. As a consequence of having an alternative to guardianship and agreements with family members, the person with a disability's legal and personal capacity to make decisions will be enhanced and respected.

91. Supporting and accommodating individuals and their rights, rather than just caring for them, will change how we view and deal with people with disabilities. This rights based approach is consistent with the developmental and inclusive approach to disability - all people have the potential to grow and develop skills and importantly to express (with support if need be) their wishes, intent and aspirations in all areas of their lives.

92. In short, SDM will provide a mechanism whereby people with disabilities can exercise control, authority and self determination over their lives and be supported and respected in doing so. With the threshold for *'in need of guardianship'* pushed to a higher limit, the opportunities for

decision making, in more areas of their lives, and the beacon of the prospect of doing so, will guide their aspirations to do so, with significant developmental and social outcomes.

93. If people have been or are denied the right to make decisions for themselves, their skills maybe under-developed. The absence of skills may be taken as an indication of capacity and lead to the appointment of a substitute decision maker. SDM will impart skills where needed, foster the ongoing development of the individual and ease people into taking or regaining charge of their own lives.

94. For the person with a disability the benefits of SDM include:-
   - Citizenship
   - Personal empowerment
   - Self determination
   - Self esteem
   - Respect for decisions
   - Control over their lives
   - Confidence in decision making
   - Confidence in rights
   - Development of decision making skills and capacity
   - Increase in areas of decision making
   - Increase in support networks

95. Families who fulfil the role of decision maker supporters will be assisted to fulfil this role and will benefit in three key ways. Firstly, greater authority and respect for their informal support arrangements; secondly, by ensuring and promoting family based arrangements that are person centred and do not subjugate the legal rights of their adult family member; and thirdly, by providing guidance and safeguards on how their rights before the law should be respected and supported.

96. Importantly, SDM re-defines how other people will think about capacity and through this extends the opportunities afforded the individual with a disability. Third parties, agencies and service

providers will be encouraged to be more person-centred and will be provided with information and strategies about how to make adjustments to how they think about and respond to the choices and decisions made or needed to be made by people with a disability. The capacity of other people to respect and nurture self determination and choice will be enhanced.

97. At the systems level, the adoption of SDM will influence the development of policies and community attitudes that are accepting of a more liberal and extended approach to capacity, within an effective safeguarding framework. This will greatly extend the opportunities afforded to people with disabilities and erode the number of restrictions on their participation as citizens, consumers and service users that they currently experience.

98. With SDM, guardianship orders will be able to be avoided in many circumstances. The need for it will diminish because individuals with a disability will have access to support, increased opportunities and skills for decision making and because others will be meeting their duty to them to make reasonable accommodations.

99. Educating people with disabilities about their rights, and also their families, service providers and the wider community, needs to be an important component of any new disability system and enhancing these rights and citizenship should be central to its design.

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7 Individualised Funding and SDM

100. The SDM agenda is linked to individualised funding, person centred planning and how to better connect people to their communities. It provides a framework that ensures supports are available to assist individuals and families to use, manage and control the resources directed to them.

101. The Terms of Reference [22] for the Inquiry include (amongst others) to assess an approach that ensures a range of support options is available, including individualised funding, and one that assists the person with disability to make decisions about their support.

102. Michael Bach is a world expert on SDM and a prolific writer on this topic. It is acknowledged that much of the views and suggestions in this section have been informed by his work and thinking. Particularly, we have relied on a paper that he presented in July 2000 at the first International Conference on Self-determination and Individualized Funding. [23]

103. At this conference he cautioned his audience about how any new 'technology', although designed with a particular goal in mind, 'can become an end, in and of, itself'; there is a real risk that by focussing on the *means* of funding, the view of their ultimate purpose might be obscured. He provides further salutary comment on this issue in the following quote:-

> '*The test of successful implementation of individualized funding is surely not simply the fact of its implementation - but whether it delivers on its promise - the promise of self-determination. And it is important that we keep this distinction clear - individualized funding and self-determination are not equate-able terms. Individualized funding is a technology. Self-determination is an ethical principle and a legal right. Individualized funding should serve self-determination. But the problem is that our technological capacity with individualized funding is outstripping our moral and ethical capacity - our capacity to hold it to account for its promise to make self-determination a reality in the lives of people with intellectual and other disabilities.*' [24]

104. The UN CRPD and SDM promote self-determination as a human right. Self-determination is inextricably linked to thinking and practice of individualised funding. But what does self

determination mean? The perspective of Michael Bach on these issues is summarised in the following table (Figure 7). This is adapted from the above mentioned paper [25] in which he identifies four approaches to self-determination and their impact on individual funding outcomes.

Figure 7 - The links between self-determination and Individualised funding

APPROACH & Definition	Individualised Funding & Planning Support	Outcome
1 CHOICE:- Self-determination is defined simply as having choices.	Any initiatives can easily meets this test - at least on paper - of having more choices.	Status and power does not necessarily change. No change in relationship.
2 CONSUMER:- Self-determination is equated with individualized funding	Funding is allocated to consumers to purchase services - and by definition - they then have self-determination.	Evaluations show that people can obtain the cash, but not self-determination. There is still no vision or direction for one's life and no power to move towards it.
3 SKILLS:- Self-determination is seen as a set of skills to make decisions	People who are self-determining are only those who meet the tests of intelligence and rationality required for making independent decisions and directing supports.	Many people with intellectual and other disabilities are excluded from self determining by this approach. People who can not meet the self-management test are not eligible for individualised funding.
4 STATUS & RECOGNITION:- Self-determination of others is respected; they have a new decision making status - regardless of skill -ands a new kind of recognition from others about a person with a disability.	Funding and planning processes need to force others to change - then look back at an individual in a new light. One that recognises their personhood, legal rights, authentic self, with a history and a future, a personal biography, with hopes, deserving of a personal vision and life plan - a person with capacity.	Real power and control is transferred through the mechanisms of individualized funding and planning support. Planning and decision-making processes foster and deepen personal relationships with family, friends and support networks.

105. The 'status and recognition' approach to self-determination is clearly the ideal, and most consistent with UN CRPD and Article 12. When the more limited options (1 to 3 above) guide implementation of individualized funding, these initiatives can fail to bring about a real change in status for neither people with disabilities and their family members, nor, in the power

relationships in the system. Self-determination is not simply about a choice, or an individual skill, or consumer power. A new disability system should operate in a way that grants respect, social and legal recognition to people with a disability. In the terms of the UN CRPD it should be the 'model' accommodation maker.

106. What then, are the systems requirements for individualised funding? Briefly, and again, drawing on the same paper by Michael Bach, in which he suggests that they are:-

- Access to independent planning support that enables people to develop a clear vision for their life - planning support that is fully accountable to individuals and to families and allows for the dialogue, time and relationship building needed to do this well.

- The resources, structural accountability to individuals and skills and values to provide such planning support and to build a foundation for self-determination.

- Funding allocated to meet individual needs for support; support needs that are defined in relation to a person's vision/direction and their plan for getting there rather than allocated on a categorical, impairment-based approach that assesses only functional needs. The latter objectifies people 'through the judging gaze of others' and ignores their personhood.

- Mechanisms that change (and improve) the day-to-day decision-making status of the person with a disability or their carer. A system that simply transfers funding between a funder, an individual's bank account and a purchased service provider maybe an individualized accounting procedure but does not reflect self-determination.

- Planning and decision-making processes that foster and deepen personal relationships with family, friends and support networks. It is these people and relationships, their personal knowledge of and commitment to the person with a disability that provides and sustains the conditions for a person's self-determination to flourish.

107. The case has been made that many forms of individual funding can fail the person with a disability and their family. Indeed, in some cases, isolation and further disempowerment is the result, especially where their support needs have been reduced to just personal care needs or a certain

number of hours of functional support. A compilation of *some* of the failures identified in the literature is at Appendix Four.

108. While individualised planning and funding are necessary conditions for self-determination, there are other funding requirements and conditions that should be important elements of a new disability system. These are:-

- Community development strategies for building inclusive communities. People require more than individualized funding to become full community members. Funding using a status and recognition approach can give them access to supports for decision making but it is not enough to change their access to opportunities, status and enjoyment of rights;

- Educational, employment, recreational, housing, and other sectors need to better fulfil their human rights obligations to include and accommodate people with disabilities. They too need appropriate resources, or else, an individual's funding will be used for these purposes and therefore, for buying their rightful place in the community, rather than having true social inclusion without a cost;

- Individuals need well-supported and sustainable support networks to assist them to exercise their legal rights, in obtaining recognition and respect of these and their personhood, in planning, making decisions, and managing their disability-related and other supports.   If all the disability support dollars in current public sector budgets were amalgamated and individualised, it still would not meet all their support needs. And if it could, this approach would not result in inclusion and the well-being that comes from family, friends, supporters and enduring relationships that are not based solely on service or paid support.

109. Independent Brokerage appears to be treated as an essential part of many individualised funding models and on the surface appears consistent with the principle of independent planning support. The UK based Social Care Institute for Excellence (SCIE), while focussing mostly on the needs of older persons, has produced a research briefing on the implementation of individual budget schemes in adult social care.[26] This report has identified the following issues:

- balancing safeguarding and workforce issues with individual choice and control;.

- advantages and disadvantages exist for carers and families.

- support arrangements are needed to ensure successful implementation.

- people with complex needs (and older people) often need greater time and support to help them get the most from individual budget schemes.

- brokerage and support is needed as emerging evidence indicates that support is more successful when it is independent of the service system.

110. This same report goes onto say,

> *'Emerging indications suggest that support brokers should provide a task-focused service, be independent of the local authority and service providers and should only be allied to the individual, their carers and community.*[27,28,29] *It is recommended that independent brokers be trained and regulated, but not in a way which stifles innovation.*[30] *It appears that including the cost of independent support brokerage in the personal budget is crucial so as to avoid the agency acting for the state rather than the individual.'* [31,32,33]

111. On the other hand, Simon Duffy and Kate Fulton (from the Centre for Welfare Reform) in a discussion paper '*Should we ban Brokerage?*' [©][34], comment on brokerage, partly in response to a growth in 'independent professional brokers' occurring in the UK alongside personalisation of care and support budgets. Their concern is that if it becomes the dominant model of support, this would 'put at risk the opportunity to create a system that is truly empowering and economically viable'. In their paper, they are careful to point out that their critique is not of other forms of support that maybe called 'brokerage'- but here-in lies a key problem - 'terminological confusion'. Figure 8 is a table version of their text on brokerage definitions.

Figure 8 - Brokerage Definitions[35]

Brokerage	Model and Explanation
1. **Broad function**	*'Sometimes the term brokerage is used just to describe the kind of support (whoever provides it) that is used to enable the citizen to be in control of their own support. This would include advising, planning, organising, managing or reviewing support.'*
2. **Budget management**	*'In this model a professional manages someone else's budget for them - but does not provide all the direct support. For instance, the Budget Minder service in Wigan provides an excellent service using this model.'*
3. **Independent organising**	*'This is the model which we refer to as Independent Professional Brokerage and which proposes that the broker is someone who plans and (initially) organises support - but who must not act as a budget manager, a care manager or as a provider of support.'*

112. Duffy and Fulton propose a community-based support system that uses all '*5 key support elements of information network, peer support, community support, support service and professional advisor.*' [36] Their view is that many people will not need the latter and those who do, may already have access to a social worker or care provider, or if not, the help of an independent professional advisor may need to be enlisted.

113. Their conclusion to the proposition in the discussion paper '*Should we ban Brokerage?*' [©] [37]

    'Should we ban the broad function of brokerage? No - not only should we not ban brokerage but we need to openly explore, test and develop any form of brokerage that seems likely to better promote citizenship and genuine Self-Directed Support. This does not mean we should increase spending on brokerage - but we must try and make better use of the current level of investment on brokerage - broadly defined.

    Should we ban Independent Professional Brokerage? No - but we would be wise to be circumspect about its benefits and the arguments presented to promote it. It seems one of the least promising approaches to brokerage and people using Individual Budgets should not be encouraged to spend their own money on it.

    Should we ban the use of the word 'brokerage'? No - any attempt to dictate how terms are used is likely to fail. However we must all try and use these terms with more precision if we are to avoid confusion and bad practice.'

114. A similar, but somewhat different perspective on the better use of existing and future resources, and for a new framework that encourages '*creactivity and spirit*' has been raised about disability

support systems in the United States of America (USA). In her article, *'Personal Agents and Independent Brokers'* Ellen Cummings from the Centre for Self-Determination [38] wrote,

> *'For a variety of reasons, the transformation of case management to support individuals in building lives full of opportunity and relationships, rather than placing in programs, has not occurred as so many had wished. In the past several years, the name case manager has been changed to support coordinator, just as teams are now called circles, but little in the work or the process has been changed. The reasons vary from place to place, from lack of will to lack of leadership to lack of resources to lack of trust to lack of knowledge. There are many in current unchanged systems, however, who very much want to get away from desks and paper in order to spend a maximum amount of their time doing something different - to have the time and support necessary to help people with disabilities build lives, but are unable to get out from under the administrative/monitoring functions within the traditional system. Creativity and spirit have become stifled in many situations and once again people who have disabilities remain in their perpetual state of waiting—waiting for change, waiting for friends, waiting for a place of their own, waiting for life. The years lost will never be regained.*
>
> *For those who work in the system and who have made a commitment to major change to support self-determination, this situation needs resolution. For those who have disabilities, the situation is unacceptable. It is time to think outside of current systems and to commit to necessary changes within those systems'.* [39]

115. Work force issues will be important, not only in respect to change, but especially if market forces produce new categories of employees and more support provider options. The temptation to regulate, train and register support providers engaged by families or the person with a disability, as a safeguard, could introduce a layer of bureaucracy that might also capture the freely given endeavours of the community, friends and family networks and act as a disincentive that will reduce choice.

> *'a further limit on choice is that posed by the workforce. …Despite this, it was also apparent that some people using Direct Payments are finding innovative solutions, particularly by*

recruiting PAs (personal assistants) from non-traditional backgrounds and drawing on the social capital of local communities' [40]

116. A new disability scheme for Australia, with a focus on rights, self-determination and inclusion; one that both adds to and unlocks the resources and creativity of families and communities and also those tied up in existing services and disability arrangements, is long overdue. The process of change, however, will need considered and careful attention. Engaging people with disabilities, their families, the community, service providers and governments and maintaining their focus on the 'higher ideal' will be extremely important.

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8 Observations

117. If we accept that a principle of any new system will be one of self-determination, then a challenge will be the transition to a system that can accommodate this; a transition that by necessity, will need to restructure the funding mechanisms for thousands of community services, with minimal impact on the people who rely on these services.

> *The absence of a sufficient range of services to support choice and control was a major theme and in all the councils there were concerns over traditional approaches to commissioning resulting in limited, standard and insufficiently flexible services. In many instances this was compounded by conservative preferences for traditional and building-based services, expressed particularly by carers who were often anxious about people needing to be adequately 'looked after' …….. The dilemma for councils very often is the need to double-fund new and traditional models of support in a transitionary period.*[41]

118. While not the subject of our submission, the above challenge is acknowledged, and based on our advocacy experience and reading, there are some observations to be made;

- How are agencies to individualize their block-funded dollars, when many of them are tied up in services delivered to groups rather than individuals? How can we provide support to individuals and families during this process, so that they do not just give up?

- How can the control over dollars and decision making be transferred to individuals and families without over-burdening them with the administration of those dollars and the management of the services they purchase?

- What will be the impact on organisations and workers under existing employment and industrial frameworks, and vice versa, on people seeking new individual arrangements, where the holder of 'their dollars' is the organisation?

- What help, provisions or guidelines will be available to individuals and families who may seek to employ their own support workers and what practical supports or funding would they be eligible for in the new scheme?

- What limits are to be placed on universal services and sectors (as mentioned in paragraph 108) in accessing, or requiring additional supports for people from, the individualised dollar?

- The public charity investment in some services is huge; physical and organisational infrastructure has been built up using these and also government funds over many years. What are the competition and pricing issues and how are they to be managed, for people with disabilities and their families, and for service providers, existing or new?

- How will the system provide real choices for people with disabilities and their families, and foster access to a variety of options? How will incentives and disincentives between new and traditional options and other barriers be overcome?

119. The SCIE briefing on the implementation of individual budgets in adult social care (see paragraphs 109 and 110) reports that research into adult long-term care reforms focusing on cash allowances in France, Germany, Italy, the Netherlands, Sweden and the UK has shown that 'although embedded within peculiar national traditions, [the] new policies share some characteristics'. Amongst others, these are;-

- a tendency to combine monetary transfers to families with the provision of in-kind services

- the establishment of a new social care market based on competition

- the empowerment of users through their increased purchasing power

- the introduction of funding measures intended to foster care- giving through family networks.[42]

120. The same research goes onto say that a comparison between schemes operating in England, Finland, Ireland and the Netherlands indicated the following as similar goals:

- increasing freedom of choice, independence and autonomy for care recipients

- compensation for gaps in existing services

- the creation of jobs in personal care services

- efficiency gains or cost savings through reduced overheads and increased competition between providers

- the shift of care preferences and use from institutional to domiciliary care (for aged care)[43].

121. Clearly there are a number of challenges for the design of the new disability system, but it is likely that any Australian scheme will also share similar characteristic and outcomes and, challenges.

122. One of those challenges is to keep people safe from harm and exploitation while promoting their rights and individual autonomy – personal choice and control over lifestyle, care and support - needs to be always at the centre. Elsewhere in this submission, some references have raised the need to balance choice with safeguarding and others, for the regulation of workers. It would be timely to harmonise the various policy goals and developments for the protection of vulnerable adults with those in the disability strategy. Otherwise, the risk is that they will be at cross purpose. This needs to be done carefully; a clear message needs to be given that adults with a disability are not all in need of protection and that abuse is not necessarily a consequence of disability.

123. There are people, however, who maybe more vulnerable to abuse due to a combination of their age, personal circumstances and mental capacity. SA's Public Advocate identified issues and strategies for improving the protection of vulnerable adults in his 2008-2009 Annual Report.[44] Safeguards will need to be responsive, graduated and personalised; keep autonomy, rights, self-determination and choice paramount; and build and maintain individual capacity, community inclusion and citizenship. Consistent with a supported decision making approach people would need to have options, information and support to make their own safeguarding decisions and only

if they are unable to do so themselves should action be taken to keep them safe from harm, abuse, neglect and exploitation.

124. Individual funding without enhancement of rights can be disempowering. New, broadly representative, community governance structures are needed to help manage the transition. Structures that engage with and address the various interests of people with disabilities, families, service providers, employees and their representative bodies and funders and that build a common ground of respect and recognition - to keep the process of transition moving and focussed on rights. Two perspectives, one from Canada and one from the UK, provide validation of this direction.

> _'Finally, we have learned in Canada that without more accountability in government for delivering on existing human rights commitments, and without a more enabling policy framework, communities will not have the tools they need to govern funding and development of supports that lead to inclusion.'_ [45]

> _'Achieving change and ensuring that everyone using social care services is able to benefit from personalisation is a human rights issue, and human rights principles and approaches should underpin every aspect of the steps to personalise support to people with multiple and complex needs. This includes commissioning, service delivery and ensuring person-centred practice. A human rights approach challenges a number of attitudes revealed in this study, and offers the way forward in ensuring that all of those people who want choice, flexibility and control are supported in their endeavours, even – or perhaps especially – when their needs are so complex and their capacity to communicate their preferences is extremely limited. Anything less would constitute a betrayal of people with the greatest needs, and a failure to realise the true transformational potential of personalisation in their lives.'_ [46]

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9 Conclusions

125. Supported Decision Making can be an integral component to the design of a national insurance scheme so that it operates within a human rights framework that promotes autonomy and self determination. For many people there is an inextricable link between decisions that they need to make about personal matters – such as accommodation, lifestyle and health care, and the choices that they need to make about services. A unified approach to decision support can work for all areas of personal decision making, and be an integral part of an individualised funding and personal disability insurance system .

126. This can be considered within the stepped model of decision making that articulates the different levels of decision support based on the level of autonomy retained for each intervention, the loss of rights and the degree of intervention by the state. There are significant gaps in our current systems to provide decision support at this time.

127. If these gaps are not addressed there is a potential for the benefits of future individualised funding arrangements to be lost if people are not supported to make choices. Because of lack of support there is a risk that people might leave decisions for others to make, continue with the same decisions that others have made for them in the past, or allow brokers to make choices for them.

128. The development of SDM should be an integral part of disability service reform, and for people who need this support, the insurance scheme, could meet the relatively small cost of obtaining this from an independent non-government organisation who have expertise in developing SDM Agreements and plans, and providing further back up to people using supported decision making arrangements when required.

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Guardianship and Administration Act 1993

(1)   The functions of the Public Advocate are—

(a) to keep under review, within both the public and the private sector, all programs designed to meet the needs of mentally incapacitated persons;

(b) to identify any areas of unmet needs, or inappropriately met needs, of mentally incapacitated persons and to recommend to the Minister the development of programs for meeting those needs or the improvement of existing programs;

(c) to speak for and promote the rights and interests of any class of mentally incapacitated persons or of mentally incapacitated persons generally;

(d) to speak for and negotiate on behalf of any mentally incapacitated person in the resolution of any problem faced by that person arising out of his or her mental incapacity;

(e) to give support to and promote the interests of carers of mentally incapacitated persons;

(f) to give advice on the powers that may be exercised under this Act in relation to mentally incapacitated persons, on the operation of this Act generally and on appropriate alternatives to taking action under this Act;

(g) to monitor the administration of this Act and, if he or she thinks fit, make recommendations to the Minister for legislative change;

(h) to perform such other functions as are assigned to the Public Advocate by or under this Act or any other Act.

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Guardianship and Administration Act 1993

Proposal for additional Section 5 principles.

Principles to be observed

Where a guardian appointed under this Act, an administrator, the Public Advocate, the Board or any court or other person, body or authority makes any decision or order in relation to a person or a person's estate pursuant to this Act or pursuant to powers conferred by or under this Act—

(a) the decision maker must begin their consideration from a presumption of capacity, that is:

  (i) an adult will be assumed to have capacity to make their own decisions unless it has been established that the person lacks that capacity

  (ii) mental capacity is decision specific. Capacity must be determined in relation to the specific function or task and the decision that needs to be made at a particular time,

  (iii) a person is not to be treated as unable to make a particular decision unless all practicable steps to help the person to do so have been taken without success

(b) consideration (and this will be the paramount consideration) must be given to what would, in the opinion of the decision maker, be the wishes of the person in the matter if he or she were not mentally incapacitated, but only so far as there is reasonably ascertainable evidence on which to base such an opinion; and

(c) the present wishes of the person should, unless it is not possible or reasonably practicable to do so, be sought in respect of the matter and consideration must be given to those wishes; and

(d) consideration must, in the case of the making or affirming of a guardianship or administration order, be given to the adequacy of existing informal arrangements for the care of the person or the management of his or her financial affairs and to the desirability of not disturbing those arrangements; and

(e) the decision or order made must be the one that is the least restrictive of the person's rights and personal autonomy as is consistent with his or her proper care and protection.

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1.   Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2.   Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3.   Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4.   Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5.   Subject to the provisions of this article, Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Table based on Articles by Michael Bach and sector experience

Individual Funding	But…………	Results in…
Individualized funding is arranged, providing a family with much needed support,	ineffective planning support, and a limited choice of service options	….simply a more complicated funding transfer -no change in status
Funds flow through an individualised funding or brokerage account rather than a contract between funder and agency,	they end up in the same place, with little change in the nature of supports provided	…..no change to the decision making status of individuals and families. If, there is mobility of funding, it is complex to arrange, and often the 'power' for its release still rests with the holder of the funds and agency.
Individualised funding (often inadequate) with limited other supports,	families are left with more responsibility than control (hiring and firing staff and dealing with turnover)	….governments saving on administrative costs; and relinquishing or discharging their responsibility because of the funding transfer.
Where those first funded and supported under a new individualized funding initiative enjoy full benefits; individualized supports; independent personal planning supports and facilitation of personal support networks	As the money becomes tighter,	…..those in need that come later find their choices are extremely limited or non-existent or experience highly restrictive funding caps. Nothing has changed, except disenchantment with the scheme and its inherit inequity.
Individualised funding with government caseworkers that are employed to control costs, or be gatekeepers,.	without independent planning support being provided, and options and choice are limited and not promoted,	…..case workers, pressed to make a placement, are likely to pre-arrange service providers.
Individualized funding exists in principle	but adults and their parents are not even aware that they have it, or that this is how their supports are funded	…..implementation of a new accounting method for governments and service providers, not the beneficiaries. People's status doesn't change, and decisions about services and how the dollars are spent are made by others.
Individualized funding contracts are rolled up, mostly for administrative ease by the funder, case workers or brokers; *and/or* service providers negotiate several funding contracts with individuals and families, and then roll them up into a funding agreement with the funding agency.	But Support workers, service providers, social workers and case managers continue to make the decisions about how the dollars will be spent.	…..easy financial reporting to the funding agency and a steady cash flow to the service provider. Portability in these case is highly unlikely, and will depend on a vacancy in another agency's rolled up contract. Often people's supports (and funds) are tied up with others and are difficult , if not impossible to extract.

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