

# Response to the Living Life My Way Discussion Paper



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## About NCOSS

The Council of Social Service of NSW NCOSS provides independent and informed policy development, advice and review and plays a key coordination and leadership role for the non government social and community services sector in New South Wales. NCOSS works with our members, the sector, the NSW Government and its departments and other relevant agencies on current, emerging and ongoing social, systemic and operational issues.

NCOSS has a vision for a society where there is social and economic equity, based on co-operation, participation, sustainability and respect.

## Overall Comments

### Aboriginal people with disability

NCOSS provides secretariat support to the NSW Aboriginal Community Care Gathering Committee (Gathering Committee) which focuses on community care services to older people, people with disability and their carers. The Gathering Committee has recently released its latest Policy Position, *Challenge Change and Choice*<sup>1</sup>, after 3 months consultation within the Aboriginal and Torres Strait Islander community. One of the new chapters is entitled *Aboriginal people with disability* and it comprises a number of guiding principles and recommendations that will improve supports to Aboriginal people and communities in NSW. Please refer to Guiding Principles 27, 28 and 29 on individualised approaches and self-directed funding for Aboriginal people with disability.<sup>2</sup>

### People with disability on the periphery

Access to person centred approaches, individualised funding arrangements and use of support pathways could largely depend on the person or their family being approached by their provider or initiating contact with a request or being encouraged by other families. The Minister's intention to appoint champions to promote person centred plans and practices in a real way directly to people by sharing experiences directly responds to this understanding.

There are however many people with disability who are not in constant contact with providers or "the system" or who do not have significant support of family or carers or whose service providers inappropriately shield them from new initiatives. Some examples could be people with disability who live in boarding houses, people who live in large residential centres, and people whose families have maintained them at home, people with disability using other sector systems e.g. Health where health professionals may not be aware of the new opportunities for responsive approaches.

While many people with disability may not require support services, many could benefit from plans with Ability Links NSW Coordinators but how will they find out? NCOSS recommends a very deliberate communication strategy that includes scenario planning to reach people with disability who are hidden and at the margins.

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<sup>1</sup> Available at <http://ncoss.org.au/resources/120704-challenge-change-choice.pdf>

<sup>2</sup> NSW Aboriginal Community Care Gathering Committee (2012) *Challenge Change and Choice*, p.11.

## **People with disability in HACC**

The Home and Community Care HACC Program provides support to around 50,000 people with disability in NSW. NCOSS is very concerned that these people with disability coming out of the HACC program will remain clients of ADHC.

The original or historical source of the person's program funding will become increasingly irrelevant and the outcomes that the person seeks to attain, being optimum independence, inclusion and participation, will be the same for any person with disability regardless where they once entered the system. This is the rationale of the person centred principles. For new people with disability requiring community care-like supports, this difference will be even more immediately irrelevant.

Evidence shows that individualised funding arrangements will provide improved outcomes for people with disability who previously used the disability specialist system. From 2014-15, people with disability who previously used HACC services could reasonably wonder why those improvements were not offered to them.

NCOSS urges that the integration of people with disability from community care is accelerated so as to avoid an inevitable two tier system: people in control with choices compared to people who use an enabling approach but who are subject to different choice and control options for mainly historical reasons.

NCOSS strongly maintains that the choice and opportunity of person centred approaches for people with disability must be universal.

## **People in ADHC provided services**

NCOSS is concerned that the opportunity to respond to Living Life My Way initiatives and person centred approaches may not have been comprehensively, deliberately and systemically extended to people living in ADHC operated group homes and other direct services. Have the people with disability and families been directly contacted with invitations to participate in these fundamental changes towards a good life for people with disability? NCOSS fears that people with disability in ADHC services may be left until last before they are included in these initiatives and this could unfairly disadvantage them in knowing about and possibly applying to convert their supports to an individualised funding arrangement from 1 July 2014.

ADHC would be cautioned never to assume that people with disability in ADHC services would neither be interested nor willing to work towards a better life.

NCOSS is aware there have been specific Living Life My Way consultations with ADHC staff and this same courtesy should have been directly and specifically extended to people with disability and families using ADHC direct services.

## **Independent Advocacy & Independent Information**

NCOSS strongly and urgently recommends<sup>3</sup> an expansion to the provision of Independent Advocacy & Independent Information to ensure the success of person centred approaches and individualised funding arrangements as well as to address

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<sup>3</sup> NCOSS (2011) *Making NSW No 1 for Fairness Pre-Budget Submission 2012-13*, see recommendation *Essential Independent Advocacy and Information for People with Disability*, p. 13. Available at <http://www.ncoss.org.au/resources/pbs/pbs2012-13.pdf>

unmet demand for individual and systemic advocacy related to non specialist issues. NCOSS, along with the NSW Disability Network Forum, is developing the role of both Independent Advocacy & Independent Information under the new system. NCOSS contends that strong, accessible, available and non-aligned Independent Advocacy & Independent Information will prove to add value to proposed support pathways in the person centred system, and will be crucial to the success of the new system. NCOSS has raised the value and role of Independent Advocacy & Independent Information throughout this submission.

### **National Disability Strategy connections**

NCOSS recommends that the success of the person centred approaches to individualised funding can only be enhanced with the strategic implementation of the National Disability Strategy NSW Implementation Plan. For people with disability, this will mean that other agencies will continue to improve their responses to disability in NSW. For ADHC, this means that the pressure on funding for individualised arrangements could be minimized as agencies appropriately assume responsibility for meaningful inclusion and participation of people with disability. Such funding can be more properly used towards a good life rather than to compensate the failings of other sectors. The National Disability Strategy NSW Implementation Plan can provide an effective framework for this if implemented, monitored and reported in line with person centred principles.

### **NSW Disability Services Act and the Role of the NSW Ombudsman**

In this submission, NCOSS makes recommendations regarding safeguards for people with disability and families under the new system of person centred approaches and individualised funding arrangements. The legislative framework and independent statutory monitoring role are critical to give effect to necessary safeguards and protections for people with disability under the new arrangements.

NCOSS urges immediate work to commence to ensure that the NSW Disability Services Act can provide appropriate legislative support and protections to people with disability and families using individualised funding arrangements. NCOSS has responded positively to past reviews of the NSW Disability Services Act, especially the principles therein and their application. It will be very important not to diminish the strength of the Act but to use this as an opportunity to improve protections and to update the Act, particularly in line with the UN Convention on the Rights of Persons with Disabilities.

Similarly, the NSW Ombudsman has provided an important arms length role for the handling and resolution of complaints as well as inquiries into operations and outcomes of programs for people with disability. NCOSS contends that these roles could become even more critical as the range of choice becomes more varied and people with disability assume more control of management over funding and support. However, the regulations governing the role and reach of the Ombudsman must be suitably amended to accommodate the new opportunities for people with disability. NCOSS recommends that the role of the NSW Ombudsman is reviewed to develop proposed extensions for appropriate protections for people with disability and families.

## Change within ADHC itself

The NSW Industry Development Fund has been designed to provide resources to assist the non-government disability services industry to prepare for the transformation arising from person centred approaches and individualised funding arrangements. This Fund has been operating since 2009. NCOSS has been recommending<sup>4</sup> funding for resources towards capacity building for people with disability and families as well as independent advocacy and independent information. NCOSS remains unclear, however, how ADHC plans to reposition or reshape itself in response to the new streamlined system.

## Responses to Questions

**Q 4.1** When are the important times that you require information?  
How would you prefer to access information?

Times that information is required:

- At entry
- At transitions
- At life changes
- At regular intervals
- At reviews
- At life stages

Information should be provided:

- In a range of accessible formats, languages and spoken word, including plain or easy to read English.
- Through a variety of people, ranging from ADHC and the service provider to independent advocacy and independent information providers.
- In person, via the phone, in brochures and on the internet.
- In culturally safe, welcoming and accessible forms with identifiable symbols and graphics to indicate relevance and appropriateness.

There should be a no wrong door approach for information. NCOSS notes the discussion paper says information exchange can be through “Ability Links NSW Coordinators, disability service system access points and person centred planning and support coordination”<sup>5</sup>. There is risk with a multitude of information providers that each could refer to a defined and specific role and then refer the information seeker to another place creating frustration and possibly exacerbating a difficult support situation.

### Caution on information provision

A menu-based phone answer system or one that uses key trigger words is extremely inappropriate for implementing the Living Life My Way or person centred initiatives. Many people with disability and their families will call information providers with a

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<sup>4</sup> NCOSS (2011) *Making NSW No 1 for Fairness Pre-Budget Submission 2012-13*, see recommendation *Essential Independent Advocacy and Information for People with Disability*, p. 13. Available at <http://www.ncoss.org.au/resources/pbs/pbs2012-13.pdf>

<sup>5</sup> *Living Life My Way* p18.

need for information without being able to exactly explain what it is they are asking for. This is a consequence of the complexity of the existing service system. They may not know that they require “respite”, “service coordination” “early intervention”, “personal care”, “domestic assistance” or “case management” unless they are already part of the system or have actually used a service.

Many people with disability have reported a shortness or abruptness in exchanges when trying to find information because they did not understand the information they were asking for and no one would take the time to discuss their situation or needs or explain what they had to do or who they had to talk to. These are conversations in which NCOSS has directly engaged with people with disability who have reached NCOSS. NCOSS always refers them to an appropriate independent information or independent advocacy provider to assist them and offers to follow up should they require it. Interestingly, they have usually already spoken to ADHC.

**Q 4.2** Key to the success of a web based information directory is the provision of feedback from people with a disability, their families and carers. How can we best capture and share individuals’ experiences and views of the supports and services they use?

The opportunity to share what types of supports and initiatives people use to create a good life with their individualised funding arrangement is extremely valuable and should be encouraged. This should be an opt-in opportunity only and not mandatory.

If there is to be a rating system for services, however, NCOSS believes that this should be carefully moderated to filter out extreme or inappropriate comments. It should also be carefully managed so it cannot be coerced or the results somehow stacked or manipulated by an unscrupulous provider.

**Q 4.3** How do you think a centralised client and service information management system should work?

**Q 4.4** What kind of information do you think government and service providers ought to be able to share (on the basis of informed consent)?

NCOSS supports the collection of information for the collation and submission of de-identified data for statistical and reporting purposes.

NCOSS is concerned that the centralised client and service information management system (or CSIM) has already been developed, funded and operationalised, very likely as an expansion of the newly upgraded ADHC internal Client Management System (CMS) for people with disability who use ADHC operated services. If this is the case, this is not made clear in the paper. NCOSS fears that the legitimate and very valid long standing complaint of having to repetitively retell one’s story has been captured as a reason/excuse to expand the CMS into the CSIM for ADHC entire target group.

NCOSS sees a range of issues with this solution:

- No alternatives to CSIM were canvassed in the paper.
- The centralised client and service information management system is not person centred.

- In person centred arrangements the focus of control, choice and opportunity is on the person and their family away from administrative restriction and bureaucratic limitation. Centralising personal information seems unnecessary and may be counter productive.
- ADHC has jumped to a seemingly ready solution rather than unpacking the problem as it has with other issues canvassed in the LLMW paper.
- Despite explicit consent requirements, the HACC experience indicates that consent remains a moot issue. Consent is still a big issue in HACC within Aboriginal and Torres Strait Islander communities, communities from oppressive regimes, families with refugee experience or families with close or distant contact with the justice system. Consent can therefore be a perceived barrier to service provision for people with disability and their families in these and other groups with similar issues. Usage data shows these groups are often proportionally under-represented in service provision.
- NCOSS has reservations about any kind of mandatory comprehensive centralised information system for the following reasons:
  - This is a systemic solution that does not respond to the needs of the person as an individual. A person centred solution to avoid inappropriately retelling a person's story could involve the required information being in the possession and control of the person with disability and their family. Please see the example *Woman & iPad* in the box below.
  - The discussion paper encourages the Support Plans to encompass the person's whole life, also including the contribution of family resources and the use of mainstream services support etc., with the Government funding being only part of the story. The CSIM is intended to include "person's support history, their support plan and funding arrangements<sup>6</sup>".
    - For many, possibly most people, the support history may simply not be relevant and could even be prohibitive. Please see the Example **Jack** below.
    - For some people and communities, a past support history could also include interactions with police or private medical interventions etc. This information may not be relevant to the provision of most support services. There are grave concerns at the security of this information held in a centralised system, especially with sharing protocols.
    - For people with holistic Support Plans as encouraged and described above, the private information contained therein will not be relevant to prospective providers and should not be kept in a centralised system unless specifically requested to do so by the person or their family.

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<sup>6</sup> LLMW p.19.

*EXAMPLE Jack:*

*NCOSS knows of a person with intellectual disability, not named Jack, who has in the past had challenging behaviour which has now been resolved for some years. Support for Jack at the time of the behaviour was very specific and sometimes difficult for providers. Despite this being part of his history, Jack continues to report that service providers treat him differently and do not give Jack the same supports and opportunities offered to his friends; he would like to do the things they do. Jack knows the behaviour is written in his file but he does not know when his good behaviour cancels out his “bad”. Jack is worried that too many people know about this. Jack’s family does not play a role in Jack’s life.*

*NCOSS would ask when the challenging behaviour would become irrelevant, when it should no longer be read by anyone now supporting Jack and why it should affect Jack’s opportunities at present in any case. When does Jack get to put his past behind him?*

- The consequence of an unintended accident or mistake in the use of CSIM information, e.g. unauthorised release of information to a third party, is with the person and their family not with the government officers or providers. Impacts could be long lasting.
- The information contained in the CSIM could potentially be dangerous for some households of people with disability. There are legitimate concerns about burglary and identity theft or worse etc. If not managed with guarantees to people with disability, the CSIM could tell people who live locally (i.e. potential or existing providers/support workers) where a person lives, who their significant contacts are, what their contact details are, bank and income details, pension and Medicare, identity particulars and how vulnerable the household is. This is potentially different from the existing system in that, under the CSIM, it could be relatively easy to determine when a household is empty, who the extended family is including their contact details and addresses, what the assets are, what the family’s interests are etc. This is potentially much more information than is contained in an Independent Plan now kept by a service provider and not provided in full to ADHC, only de-identified before submission for statistical purposes.
- Support Plans will be encouraged to include mainstream and disability specific service providers and may include non-profit as well as for profit and commercial operators. This multiplies the risk and exacerbates the vulnerability of the household of the person with disability when sharing an individual’s personal information.
- Personal information that is centrally held and can be accessed from anywhere can be especially problematic for people who live in small communities where privacy can be difficult to protect; even when access to that information is restricted. This applies to regional and rural communities as well as culturally and or religiously identified communities.



### **Access to a Person's Record**

NCOSS is constantly reminded of the diversity of the people whose records could be held by a potential CSIM. Many may not have access to or be able to privately use a computer to access their on-line Record. NCOSS agrees that for some this could be a transitory generational problem but for others the problem will be long term or permanent. Regardless of the nature of the inability to access, that fact that access is planned to be freely and 24/7 available to some and not others immediately sets up potential for unintended disadvantage among people with disability.

### **Lessons from HACC**

The discussion paper does not acknowledge that there are different needs and purposes for different levels of information. It does not have to be an all or nothing proposition. The HACC experience provides us with some very salient lessons and direction.

- The HACC Program developed the Client Information and Referral Record (CIARR). The CIARR is a four page form with all the regular information needed by ADHC and service providers to assess eligibility, ascertain access and priority. With the person's consent, this information can be shared between potential service providers. After the service provider accepts the HACC referral on the CIARR, the person is then asked to provide more and very specific information required by that organisation to arrange that specific service. This level of information is different for each service type, e.g. community transport requires differing information from meals on wheels or domestic assistance or personal care or community options or overnight respite.
- The Community Care Access Point has also piloted information referral, keeping client information sharing between potential providers to the basic minimum. Only after a provider confirms they are prepared to provide access to a potential client based on basic CIARR style information, then further client information is forwarded to the provider organisation.

### **Person in control of information**

NCOSS recommends that the information could be possessed and controlled by the person and their family, but perhaps in a way that would answer standard information collection requirements made clear before plans are developed. The offer of retaining the person's information in the CSIM could be made but must not be mandatory. ADHC would be well advised to seek legal advice on insurance and other liabilities surrounding the holding of such comprehensive personal and private information on households over which ADHC has no responsibility or control (i.e. people not living in ADHC operated services).

NCOSS urges ADHC to consider how it deals with information about an individual's support history before progressing on its seemingly designated path.

NCOSS contends that a general rule would be that accidents and mistakes cannot occur with personal information that is not held by a centralised system. But a centralised system that holds only general information, with personal information retained within the control of the person, prevents the severity of any departmental

accident, mistake or liability and allows the person to decide what information is shared, at what time and with whom

**EXAMPLE *Woman & iPad:***

*When NCOSS asked the NSW Aboriginal Community Care Gathering Committee about this issue, a member described how a young Aboriginal woman used an iPad to solve her problem. This young woman had physical disabilities with high support needs and found it very difficult to constantly retell every new personal care worker how to provide her very intimate personal support. So she had her regular care routine videoed on her iPad. Now, every time a new worker or a replacement worker or a casual worker commences (sadly she reports this happens fairly often), she just shows them the video and they know exactly how, where and why she wants her personal care provided. This young woman remains in control of who sees this information, when they see it, where they see it, she can change it at any time and it is entirely person centred. Her privacy is respected and confidentiality is assured.*

**Checking individual funding arrangements**

NCOSS supports the ability of a centralised system that enables the person with disability to check their funding arrangements online and to track funding progress at any time. This would equally apply to any agent nominated by the person with disability. This arrangement, however, must never be a routine consent and must be carefully informed.

**NSW Aboriginal Community Care Gathering Committee feedback**

As explained above, NCOSS discussed these questions with the NSW Aboriginal Community Care Gathering Committee. Their feedback on Question 4.3 included:

- Concern regarding confidentiality, as explained above
- History:
  - A person's history of engagement with government agencies may negatively impact their willingness to engage again OR
  - A record of irrelevant long past issues may affect how a person is treated or prioritised by a worker
- How the information will be used. This is not explained in the discussion Paper.
- Choice: This is only real if it is responsive to the needs of Aboriginal people as well as culturally safe and welcoming. Choice is important in how the plan can be developed and how the money can be spent. Many Aboriginal communities already champion a person centred approach to supporting a person with disability but without the necessary resources to fund it.
- Impact and effect on Aboriginal communities

The Gathering Committee's feedback on Question 4.4 included:

- With informed consent, government and service providers ought to be able to share "only what I tell them they can share."
- Aboriginal people may not even take up services because of their concern at government sharing information.

**Q 4.5** What are the best strategies for increasing the inclusion of people with a disability in the activities available in their local community?

### **Ability Links NSW**

NCOSS supports the Ability Links NSW initiative. NCOSS also notes that the population of people with disability that Ability Linkers<sup>7</sup> (shorthand for Ability Links NSW Coordinators) support may differ somewhat from those supported by the Local Area Coordinators in Western Australia on which they are modeled and the Local Support Coordinators now working in some areas in NSW. The LACs in WA do not seem to discriminate towards lower needs people with disability and will annually support between 50 – 65 people whereas Ability Linkers are likely to be supporting up to 129 people per year, with the Ability Linker role aimed at people with disability requiring information and assistance to access mainstream and other supports and people with disability eligible for but not in receipt of support services. NCOSS understands that people with low support needs may be included in the third year of Ability Links implementation and people with higher support needs will be referred to case management. Existing Local Area Coordinators in NSW do not seem to discriminate towards lower needs people with disability either and, employed by ADHC, LSCs are remunerated on a much higher wage scale compared to the proposed Ability Linkers.

It is anticipated that the first stage of Ability Linkers will be implemented by the end of 2012. In the absence of the implementation of other areas of the support pathways<sup>8</sup> (access points, planners, case managers, support coordinators etc.), there is real peril that Ability Linkers will be the all-purpose “go to” people, that expectations on the Ability Linkers could be unreasonable and that their intended role could consequently fail. As people with disability and their families correctly come to expect that they can prepare for a more person centred approach from 1 July 2014, they are increasingly likely to contact these new Ability Linkers regardless whether this is appropriate.

### **Language is important**

A person without disability does not participate in the “activities available” in their local community. He/she simply participates in the local community, doing things that one prefers to, has to or chooses to do. It is very important for ADHC in a leadership role, in a person centred paper for people with disability, not to use language that would not otherwise apply to anyone else, wherever possible.

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<sup>7</sup> Information on the likely role of Ability Links NSW Coordinators has been drawn directly from the Ability Links NSW Tender documents released earlier in 2012.

<sup>8</sup> Refer LLMW Paper Page 16 Figure 2

- Q 4.6** What is the best way of providing access to the disability service system?  
**Q 4.7** What functions do you think sit best in common access points?

### **Different responses for new and existing people with disability**

NCOSS notes the proposed core roles of the access points. What is not clear in the LLMW paper is that there will be a difference in how access points and other parts of the support pathways relate to new people with disability approaching ADHC for the first time and those people with disability now using the specialist disability system. For example, the support needs assessment could be used to identify the support needs of a new entrant applying for supports but will be irrelevant for people with disability wishing to convert their existing provision into an individualised funding arrangement. The application of the needs assessment is not clear in the paper.

### **Common access point**

NCOSS favours a no wrong door approach in tandem with any proposed common access point. NCOSS further recommends the lessons learnt from other relevant analogous sectors.

Early lessons from the Aged Care Assessment Teams:

- Bottleneck waiting list, with concomitant effects on provision etc.
- Preferential channeling of people to some providers
- Very good follow up of clients by some teams
- Access in regional and rural not as effective in the early years
- Poor access by Aboriginal and Torres Strait Islander people, patchy cultural appropriateness
- Poor access by culturally diverse communities

Early lessons from Carelink:

- Sometimes, inappropriate use of key words as triggers
- Wide variation in quality of responses
- Unable to refer from outside calling area, sometimes poor follow up
- Often unable to refer outside specific program area
- Carelink database not available to the public

### **Support needs assessment**

Paragraph 82 indicates that the support needs assessment informs and influences the direction of the person centred plan. While the support needs assessment will certainly provide an important and professional appraisal of the person's needs, it will not determine the person's priorities, their preferences, the way in which they decide to strive for a good life or use a strengths based approach. It is a deficit approach that will not identify their attributes and talents. Consequently, NCOSS cautions against the use of this assessment being used to determine or direct the individualised funding targets, as this contradicts the person centred approach and the move towards effective and efficient self-directed funding.

There appears to be ambivalence within the discussion paper regarding references to the person's plan. If the person's plan can be holistic, as suggested early in the paper, and includes personal and family resources and mainstream supports as well as specific services purchased by government funding, then a deficit based needs

assessment may inform but will be inappropriate to regulate the direction of a person's plan.

### **Roles of the access point**

NCOSS remains unconvinced that access points should combine incompatible roles that create potential environments of conflict of interest such as

- prioritisation and allocation of individualised funding *with* fund holding or
- planning *with* prioritisation and allocation of individualised funding or
- planning *with* support coordination

The inter-relationship between the access point and Ability Linkers is not yet clear or well defined nor are other such relationships in the support pathways.

**Q 4.8** Do you support a life stage approach to guide person centred planning?

**Q 4.9** What are some of the things that should be considered in designing a life stage approach?

**Q 4.10** Do you think that there should be some supports that are so important that they must be included in a plan?

**Q 4.11** How should the life stage approach be modified to accommodate people who have adult onset of disability or degenerative conditions?

### **Life stage approach**

NCOSS supports a life stage approach to planning but as a general guide only, not obligatory or determinative. People with disability must be able to make their own decisions about their priorities and interests and must not be locked into what is considered by others to be appropriate for them, if not of the person's choosing.

### **Key areas for a person's plan**

Figure 3 on page 27 in the discussion paper illustrates the key areas the planning process should consider. NCOSS agrees that these are areas for consideration but not necessarily for mandatory inclusion nor specific priority. NCOSS recommends the inclusion of cultural resourcefulness as a key area – see below.

Paragraph 93 suggests four options the Government is considering for guiding the planning process. NCOSS comments on each of the points follows:

- NCOSS recommends the inclusion of independent advocacy and independent information in “the provision of information, guidance and advice during the support needs assessment and planning processes”
- NCOSS opposes the Government specifying life stage outcomes and support types, except where clearly identified as a guide. As previously explained, people should not be locked in. Any obligatory implementation of life stage outcomes and support types in no way responds to a person centred approach and contravenes the purpose of the discussion paper.
- NCOSS does not support set criteria for the funding components of a person centred plan, aside from contractual or logistical considerations i.e. accountability, monitoring and legal issues. This means that NCOSS opposes

mandatory pre-determined support types at life stages for the reasons stated above. John Waters CEO of In Control UK, in his Sydney Seminar on Resource Allocations in Self-directed funding on 21 June, stated that people with disability have the greatest incentive to make the funding dollars work the hardest and that this will work best if Government “gets out of the way” and lets it happen.

- If the person’s plan includes information from all the key areas in Figure 3, then the Government’s approval of the person’s plan should explicitly cover the Government funding only. The Government must have no right, jurisdiction or responsibility over any other part of the person’s plan.

### **NSW Aboriginal Community Care Gathering Committee Input**

The following Guiding Principle<sup>9</sup> recommends an acceptable consideration for every individual plan of an Aboriginal or Torres Strait Islander person with disability.

#### **Work from strengths**

Guiding Principle 24: Services and supports to Aboriginal people with disability and families must include the capacity and resources to enable participants to build cultural resourcefulness. The Gathering Committee acknowledges the cultural strengths of Aboriginal people. Aboriginal people with disability and families require supports that allow and encourage self sufficiency within the Aboriginal family unit.

**Q 4.12** What range of options should be available to support people in person centred planning?

**Q 4.13** Should organisations involved in delivery services also be involved in person centred planning?

**Q 4.14** What other decision support and capacity building resources will people with a disability, their families and carers need in order to identify and choose their supports?

### **Planning options**

NCOSS recommends that planning support must be funded separately from a person’s support funding, must be available from a variety of sources of the person’s choosing and that planners must have high expectations.

The roles of service provision and planning are not compatible and can give rise to deliberate or unintentional conflict of interest. This would serve to limit the options for the person with disability.

### **Who participates in the person’s plan?**

NCOSS supports that the person with disability must be able to choose who participates in their person centred planning process.

<sup>9</sup> From *Challenge Change and Choice* Policy Position <http://ncoss.org.au/resources/120704-challenge-change-choice.pdf>

## **Safeguards**

There is a clear role for independent information bodies in providing non-aligned information in preparation or during development of the person's plan. There is a clear role for independent advocacy organisations in providing non-aligned advice and safeguards surrounding the person's plan. This could serve to identify early and easily managed problems before escalation, could provide necessary assurances, could provide additional advice and guidance, could work with the person and providers especially where there are issues within the family that are separate from the funding and supports. In this way independent advocacy organisations will add value to the existing support pathways and service providers systems.

## **Other decision support and capacity building resources**

There is a clear role for independent advocacy and independent information organisations to assist in decision support and capacity building. Such organisations with expertise and knowledge of specific disabilities, that are of and for people with disability, could assist people with disability and families to aim high, to envision a good life and to look first to community and mainstream inclusion and participation, outside the specialist disability service provider system. Independent advocacy and independent information organisations can assist people and families to prepare for the new person centred approaches, to be self-directing, to use their own resources and to understand how to extend their own capacities.

## **Beware a new complex system**

NCOSS cautions against simply replacing the existing complex disability "postcode lottery" system with another rebadged but still complex system. An effective new system will be streamlined, as enabling of people as possible, with clear and known rules, a minimum of administration and maximum outcomes for people with disability.

**Q 5.1** Are there any disability supports and services which would be more appropriately funded through a direct funding allocation to a service provider?

NCOSS contends that several disability supports and services should receive direct funding allocations:

- Independent advocacy
- Independent information
- Early intervention services, see below.
- Interpreter services, including spoken and sign language interpreters
- Non-aligned planning services

## **Early Intervention**

NCOSS supports the recommendation of Pathways Early Childhood Intervention Services Inc. that Early Intervention for children with disabilities must be directly funded and must remain separate from their individualised support arrangements.

## **Short term discretionary funding pool**

NCOSS further contends that there should be a small discretionary direct funding pool for use during the transition period and by exception only. This discretionary pool should be allocated on a strictly time limited case-by-case basis and used for such functions as:

- To sustain services in remote areas for a limited time period
- To sustain services to small or identified populations e.g. rural Aboriginal communities
- To overcome unforeseen unintended consequences

#### **Q 5.2** What should not be paid for from an individual's funding allocation?

An individual's funding allocation must not pay for:

- Advocacy: either individual or systemic
- Information, including that research on a person's behalf to assist their plan
- Planning or additional advice
- Interpreter services, language services and sign language interpreters
- Other services that make information, assessment & planning sessions etc. accessible to the person and their family e.g. use of communications devices.
- Complaints or appeals processes
- Any services that are now not part of the disability support e.g. education, health, etc.

#### **Employing a family member**

NCOSS supports the capacity of a person's funding arrangement to employ a family member. This must be subject to appropriate transparency, legal, contractual, industrial relations and monitoring obligations. If a family member is paid, then the family member is staff for that person with disability. NCOSS acknowledges that this arrangement may be inappropriate in some cases but, where the person with disability chooses this, it also may also be appropriate in many cases to extend the capacity of the person to participate in the community and the family to support them. A very good and well known example of where this has worked well for a person's individual funding is the publicly documented case of Sylvana Mahmic's son Karim, who pays both his brother and his cousin for a few hours each week.

#### **Q 5.3** What rules and accountabilities do you think should be applied to fund holding?

In the same way financial counselors and tax agents are accountable and liable for professional practice, fund holders must be liable for any contracted work pertaining to an individual's funding allocation. Equally, similar to tax agents, the loyalty of a Fund holder must first be to the person with disability. There must be absolute disclosure and transparency of any connections to service providers or other possible conflicts of interest.

Fund holders must be obliged to remain solvent, to report to the person as required and to take their direction from the person.

#### **Q 5.4** Are the proposed principles for the use of individualised funding reasonable? If not what should be changed or added?

NCOSS considers the proposed principles for the use of funding to be generally reasonable, as long as they are deliberately and exclusively applied in an enabling rather than a limiting capacity.



NCOSS cautions that people should be able to try new approaches, so value judgments about what works for whom can be prohibitive e.g. as in supports which have been proven to be ineffective or harmful.<sup>10</sup>

**Q 5.5** What assistance would you need to manage your own funding and coordinate your supports?

NCOSS recommends that people with disability and families should have a range of choice options surrounding who their fund holders and other financial and support intermediaries could be. See previous comments regarding supports needs to manage funding and supports.

**Q 5.6** What kinds of capacity building opportunities should be available for people with a disability and their families and carers?

In support of previous recommendations on independent advocacy and independent information, NCOSS has documented the capacity building opportunities necessary in the NCOSS 2012-13 Pre-Budget Submission page 13 under the heading *Essential Independent Advocacy and Information for People with Disability*. Available at <http://www.ncoss.org.au/resources/pbs/pbs2012-13.pdf>

**Q 5.7** How do we best support people to assume more control over the management of their funding and support arrangements?

The best way to support people to assume more control is to simplify the system, to reduce the amount of administration and paperwork, to enable personal decision making and to validate the person's decisions. The more the system pre-determines the plan, the less likely the person is to assume control. NCOSS contends that it is vitally important to instill confidence in people with disability to move towards self-direction and that the system will not consequently slap them down.

In summary, people will assume more control over the management of their funding and support arrangements if:

- they have confidence their decisions will be listened to, respected, validated and implemented, and that the decisions can be changed and amended as required.
- the rules and obligations are clear, known upfront, streamlined and as straightforward as possible
- people can seek independent non-aligned information to inform decisions
- people can seek independent non-aligned advocacy, advice, guidance and assistance to navigate and negotiate their plans etc. when needed
- the development and implementation of person centred plans is not over-regulated

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<sup>10</sup> LLMW Paper p. 34 paragraph 114

**Q 6.1** What kinds of support does the service sector need to change the way services are designed and delivered?

NCOSS supports a vibrant service sector to respond flexibly to the needs of people with disability. Certainty and responsiveness have been major factors in the move to person centred approaches for people with disability.

NCOSS sees the move towards person centred approaches as shifting funding certainty away from service providers towards people with disability. This represents a fundamental change in the system.

**Q 6.2** How do you believe the quality of supports and services should be regulated?

**Q 6.3** How do we balance freedom to choose a support and service provider with ensuring the quality of the support or service?

### **Anomaly of the *funded service***

An inherent anomaly can be found in the discussion paper regarding the issue of quality. From 1 July 2014, a dual system will operate whereby some people with disability will have individual funding arrangements and some people with disability will continue to use block funded services. This dual system effectively operates at present under a number of existing programs that currently offer self-managed packages.

While the take up rate of individualised funding is expected to be initially quite low at 10%, the NSW State Plan, *NSW 2021*, anticipates that by 2019 all people with disability will be using individualised funding arrangements.

The inherent anomaly is the reference to *funded services*. Services that are directly funded by government, *funded services*, will effectively only operate until 2019 or until the full implementation of the National Disability Insurance Scheme NDIS. From 2019 on, most services and supports provided to people with disability will simply be purchased, like any other good or service. Therefore, the reference to funded services can only occur during the transition period before conversion to a personalised or individualised funding delivery system.

### **No mandatory purchase of supports**

NCOSS opposes the mandatory obligation for plans to purchase only supports validated under a quality framework, for at least the following reasons:

- Contravenes person centred principles.
- Severely restricts choice, range, scope and options for people with disability.
- Effectively disallows self-directed funding and independent recruitment.
- May result simply in a re-badged existing system i.e. nothing really changes in service provision or control for people with disability except names and titles.
- Prohibits real innovation.
- Can serve to lock people with disability into segregated services, especially if there is no real incentive for other non-disability organisations to become quality validated.
- Could artificially force price rises.

### **Quality essential for people with high support needs**

NCOSS absolutely supports quality assurance for people with very high support needs requiring intensive support services. For people with disability who rely on such intensive supports, the knowledge that those supports have already met quality standards could be critical to their health and safety as well as quality of life.

### **Choice of quality**

For other people with disability and families, the level and extent of quality should be their decision. It is not reasonable that people with disability are artificially locked into highest quality services for each and every intervention under a future system when the supports and services provided to them at present are not similarly required to do so. For example, the local ballet class must not be required meet any disability quality standard simply to accept a ballet student with disability.

### **Freedom of choice prevails**

There must be “no balance of freedom of choice with quality of support”. Freedom of choice must prevail. The only possible exception would be in cases of significant risk as explained above for people requiring intensive service provision. NCOSS also believes that they too must have the opportunity to exercise informed choice.

The principles of person centred approaches will ensure that more responsive and better quality supports will attract more people with disability to use them. If that fails, there may be an opportunity for people with disability to make changes to the supports they use. Freedom to choose must be the primary determinant under a person centred system.

The present system has worked on quality improvement for many years and still the Productivity Commission produced fairly grim general findings. This new approach offers the best opportunity in decades to initiate transformative improvements to responsiveness and quality within services and supports to people with disability.

### **A question of SAFEGUARDS**

NCOSS contends that it is less a question of quality of service and more a question of safeguards for people with disability and families. Pre-emptive investment in quality assurance for services could prove transitory unless people with disability see the value of positive change within existing services. This is something that the disability service industry must manage and deliver.

NCOSS recommends deliberate investment in strategies that provide explicit safeguards to the use of goods and services with an emphasised capacity to respond to people with disability and their families. Such strategies could include:

- access to consumer safeguards;
- accessible transparent feedback, complaints and appeals mechanisms;
- community development strategies towards inclusion and participation strategies;
- review and amendment to the NSW Disability Services Act; and
- review and amendment to the role of the NSW Ombudsman