



Supporting carers to live life their way

Submission to the NSW Government's
consultations on Person Centred Approaches

August 2011

Summary of recommendations

1. Carers NSW recommends that the *NSW Carers Charter* be used as a framework in the conception and introduction of person centred approaches to ensure the real and systematic recognition and inclusion of carers in the person centred system.
2. Carers NSW recommends that staff involved in supporting person centred planning are trained to negotiate likely tensions that will arise between the choices and interest of carers and people with a disability.
3. Carers NSW recommends that clear and transparent resolution processes are in place to resolve conflicts arising from the planning process.
4. Carers NSW recommends that carers are provided with access to advocacy services, in their own right as carers.
5. Carers NSW recommends that carers be provided with access to the training they need to support their engagement in person centred planning, including training in communication, conflict resolution, rights, advocacy and person centred planning and approaches.
6. Carers NSW recommends that carers be provided with information online, face-to-face and through information sessions addressing the range of issues relating the role of the carer in person centred planning.
7. Carers NSW recommends that the sharing of person centred planning experiences be facilitated through the establishment of an online forum, the publication of case studies and the facilitation of mentoring relationships.
8. Carers NSW recommends that resources are allocated to provide carers with the support they need to engage in person centred planning, which may include support planners, intermediaries, counselling, respite and transport.
9. Carers NSW recommends that carers have the choice of managing their own funding, and of opting out of managing their own funding.
10. Carers NSW recommends that transparent decision making processes are implemented and that decisions are clearly communicated to those affected.
11. Carers NSW recommends that carers be provided with access to the training they need to develop the skills to manage their own funds, including basic accounting, budgeting and computer skills.
12. Carers NSW recommends that carers be provided with information online, face-to-face and through information sessions addressing the range of issues relating to managing their own funds.
13. Carers NSW recommends that resources be provided to support carers to manage their own funding, including templates, check-lists, software and a hotline.
14. Carers NSW recommends that carers are included in the assessment process of the person with a disability for whom they care, to a degree which reflects the level of their involvement in the care and support of that person.

15. Carers NSW recommends that carers have the right to their own assessment as carers, and access to services and supports in their own right, when required.
16. Carers NSW recommends that the implementation of carer assessments is supported by carer awareness training for assessors, and by the provision of education and information to carers.
17. Carers NSW recommends that the prevalence of carer assessment be monitored to ensure appropriate uptake.
18. Carers NSW recommends that carers have the right to request reassessment of themselves, or of the person with a disability.
19. Carers NSW recommends that reassessment be triggered by significant transition points or changed circumstances.
20. Carers NSW recommends that carers have access to transparent and clear resolution processes in the case of a disputed assessment.
21. Carers NSW recommends that assistance and direction given to providers in the transition to a person centred system support the systematic recognition, inclusion and support of carers.

Introduction

Carers NSW is pleased to provide a submission on the introduction of person centred approaches in NSW. Representatives of Carers NSW participated in the Person Centred Approaches Summit held in July, and are following the introduction of person centred approaches closely, and with some optimism.

This submission will address some of the questions posed in the discussion paper, with a focus on carers, their role in a person centred system, and the importance of ensuring that they too have choice and control, and are able to live life their way.

Carers NSW recognises that the interests of people with a disability and their carers are closely interrelated, and that many of the recommendations made in this submission will be equally relevant to people with a disability, particularly those relating to the supports and resources that will be required to enable effective engagement with person centred approaches. However, as this submission has carers as its focus it will primarily address their role and needs in a person centred system.

1. A person centred system – our vision for carers in NSW

A truly person centred system would mean real change for carers of people with a disability and would transform the experience and impacts of caring for a person with a disability. Carers NSW envisages a system which has people with a disability and their carers and family at its centre. In this system carers would:

- have access to the services and supports they actually need and want
- have more choice in their caring role, in regards to what caring responsibilities they take on, how much care they provide and for how long
- be able to balance the care that they provide with other supports, particularly from formal services
- be supported to participate in employment, education and the community
- enjoy improved physical, mental, emotional, financial and social wellbeing
- be able to live life their way.

Carers NSW envisions a system in which carers are finally recognised, included and supported, and the principles of the *NSW Carers Charter* are made reality. Carer recognition and inclusion would be the rule, rather than the exception, and would be a fundamental part of person centredness, not an afterthought or optional add-on.

The improvements and outcomes described here for carers are Carers NSW vision of what a person centred system, which has both people with a disability and carers at its centre, can achieve for carers. The degree to which this vision becomes reality will depend upon the way in which person centred approaches are adopted in NSW, the degree to which a truly person centred system which has carers at its heart is achieved, and the resources that are made available to support people with a disability and their carers.

2. Carers (*Recognition*) Act 2010 and person centred approaches

The principles of the *NSW Carers Charter* must inform the conception and introduction of person centred approaches in NSW. The *NSW Carers Charter* was established by the *Carers (Recognition) Act 2010*, and establishes the following principles:

- (a) The valuable social and economic contribution that carers make to the community and the persons for whom they care should be recognised and supported.
- (b) Carers' health and wellbeing are to be given due consideration.
- (c) The views and needs of carers and the views, needs and best interests of the persons for whom they care must be taken into account in the assessment, planning, delivery and review of services provided to persons who are cared for.
- (d) Carers should be referred to, and made aware of, appropriate services to assist carers in their caring role. Such referrals should be made after an assessment of the needs of carers or as part of the assessment or provision of services to the person being cared for.
- (e) The relationship between carers and the persons for whom they care should be respected.
- (f) Carers are to be acknowledged and recognised as having their own individual needs within and beyond their caring role. This acknowledgement and recognition is to take into consideration Aboriginal or Torres Strait Islander culture, age, disability, religion, socio-economic status, cultural differences, gender identification and place of residence.
- (g) Children and young people who are carers have the same rights as all children and young people.
- (h) Children and young people who are carers face additional difficulties and burdens and should be supported in overcoming these difficulties and burdens.
- (i) Carers should have the same rights, choices and opportunities as other Australians.
- (j) Carers' choices in their caring role should be supported and recognised, including the recognition of carers in the assessment, planning, delivery and review of services that impact on carers and their role as carers.
- (k) The additional difficulties faced by remote and rurally based carers caused by isolation should be recognised and acknowledged
- (l) Support for carers should be timely, responsive, appropriate and accessible.
- (m) Carers' unique knowledge and experience should be acknowledged and recognised.¹

These principles should act as a framework for the recognition and inclusion of carers in the conception and introduction of person centred approaches. The NSW Government must ensure that the *Carers (Recognition) Act 2010* is upheld and actively promoted in the transition to person centredness.

Recommendation 1: Carers NSW recommends that the *NSW Carers Charter* be used as a framework in the conception and introduction of person centred approaches to ensure the real and systematic recognition and inclusion of carers in the person centred system.

3. Person centred planning

“Person centred planning puts people in the context of their family and their community. It is therefore not just the person themselves that we seek to share power with, but family, friends and other people from the community who the person has invited to become involved”.ⁱⁱ

Positive outcomes for carers will depend on person centred planning being implemented effectively, and on carers having more choice and being better supported as a result. Person centred planning in NSW must look at the person in the context of their family and community, be inclusive of carers, and respect the right of the carer to live life their way, if it is to lead to sustainable and real benefits for people with a disability and their carers.

3.1 How should the differing needs of the person with a disability, and their families or unpaid carers be considered in the planning process?

The person with a disability, their carers and family must all be included and engaged in the planning process. Carers and family members affected by the planning process and its outcomes should have their voices heard. The needs of those providing support must be considered alongside those of the person with a disability, as should their choices.

Including carers in the planning process is critical to ensuring that carers experience positive outcomes from person centred planning, and to reduce the potential for negative impacts. A 2009 study from the United Kingdom on the impacts of individual budgets on carers indicated that positive outcomes for carers “were clearly associated with their involvement in planning service users’ support arrangements”.ⁱⁱⁱ

People with a disability have a right to make choices about how they live their life, a right which will be supported by the introduction of person centred approaches. In protecting or supporting the right of the person with a disability to live life their way, it is important that the right of the carer to do the same is not overridden. Decisions made about what support the carer will provide must not be made without them.

Carers NSW anticipates three different kinds of disagreements or tensions that may arise in the person centred planning process, relating to:

- conflicting best interest
- conflicting perceptions of best interest
- conflicting choices of individuals relating to their own lives.

Those supporting and implementing person centred planning must be prepared to navigate these tensions. Resolution processes must be in place for when these tensions are not successfully resolved within the planning process.

3.1.1 Disagreements on what is in the interest, needs or capacity of the person with a disability

It is likely that disagreements around what the person with a disability needs or is capable of will be common, including between the carer and the person with a disability, or another party. These disagreements may be particularly common for those new to person centred planning, particularly when the carer has been caring long term, and has provided the majority of care to the person with a disability throughout their life. Carers may disagree with the choices made by the person with a disability, particularly regarding their capacity and needs.

Panellists at the Person Centred Approaches summit shared their own experiences of this tension. These personal accounts demonstrated that although such disagreements or misgivings may be common, they can be overcome if carers, people with a disability and other parties in the planning process are treated with respect, have their voices heard, and have access to the information, education and support they need.

As established in the *NSW Carers Charter*, “carers’ unique knowledge and experience should be acknowledged and recognised” and “the relationship between carers and the persons for whom they care should be respected”.^{iv} The experience, knowledge and expertise of the carer must be respected in person centred planning. This does not mean the carer is never wrong, but that the carer should not be summarily dismissed as wrong or overprotective because they disagree with others. Sanderson clearly states that families must not be caricatured as one dimensional in person centred planning, and that their good intentions must be trusted.^v Like other parties in the process they come from a unique perspective, which must be understood, and they may need time, education and support to come to terms with the choices of the person with a disability, and to recognise their capacity. Like the person with a disability, carers should be able to make mistakes and to take risks. Like the person with a disability they may also take time to build up confidence in the process and in the other parties involved.

3.1.2 The best interest of the person with a disability conflicts with the best interest of the carer

It is important to recognise that in some cases what is in the best interest of the person with a disability may not be in the best interest of their carer. For example, a person with a disability may best have their needs met by receiving a certain degree of support, or certain kinds of support from their carer, in addition to or in the absence of, adequate formal supports. However, the provision of this degree of support or these kinds of supports may not be in the best interests of the carer, and may have direct and significant negative impacts on their health and wellbeing, their participation in education or employment or other aspects of their life. This scenario is particularly likely when the person with a disability cannot access funding or other resources adequate to their level of need, and thus relies on the support of their carer and family.

In these scenarios, the process of person centred planning should allow these issues to be raised, explored, and a solution realised. It is important that there are information and resources that can be drawn upon by people involved in the planning process to ensure that

this is possible, and that there are high levels of awareness of carers own needs as individuals, and respect for their interests and their right to health and wellbeing.

Access to adequate resources and formal support services will be crucial to resolving situations of this nature. Inadequate funding or resources will undermine the person centred planning process, and it will be both people with a disability and their carers who suffer as a result. Although compromise and innovation may resolve many of these conflicts, neither the person with the disability nor their carer should have to pay a high price to make such compromises. Exclusion from the workforce, loss of employment, injury or poor health and wellbeing are just some examples of the compromises that neither the carer nor the person with a disability should have to make.

3.1.3 The carer's choices about their own life conflict with the person with a disability's choices about their own life

It is also important to acknowledge that in some cases the choices of the person with a disability will conflict with the choices of the carer relating to their own life. This type of scenario is similar to the previous example. In this case, instead of the best interest of one party conflicting with the other, it is the choices of the two parties which conflict, and the rights of each to live life their own way which are in competition.

As with the previous example, robust person centred practice, which has the carer as well as the person with a disability at its centre, should be able to resolve such tensions, and find a solution where both the person with a disability and their carer are able to choose how they live their life, assuming adequate funding and resources are available. Again, neither party should have to seriously compromise their own wellbeing, or their own right to choice in order for a solution to be reached.

Recommendation 2: Carers NSW recommends that staff involved in supporting person centred planning are trained to negotiate likely tensions that will arise between the choices and interest of carers and people with a disability.

3.1.4 Need for advocacy and resolution processes

Whilst most conflicts should be able to be resolved in the person centred planning process, there is a need to ensure that when an impasse is reached there are processes and supports in place to allow a resolution to be achieved.

Advocacy services for carers will need to be introduced as carers do not currently have access to individual advocacy services. These will be essential to ensure that the rights and choices of carers are protected in a person centred system. Advocacy services will be particularly important to carers who are limited in their ability to represent themselves in the planning process, or in their ability to make choices or plan for the future. Carers need to be able to access advocacy services for themselves in their own right as carers, as well as being able to access advocacy services on the behalf of the person with a disability when necessary.

Recommendation 3: Carers NSW recommends that clear and transparent resolution processes are in place to resolve conflicts arising from the planning process.

Recommendation 4: Carers NSW recommends that carers are provided with access to advocacy services, in their own right as carers.

3.2 What information and/or support do people with a disability and their families need to participate in planning?

Carers will need information and support to understand person centred planning, and to be able to effectively engage in the process. Carers currently have varying levels of understanding of what person centred planning is, and will require varying levels of support to be able to understand and engage in the process. Some carers may require little support. Other carers, particularly those who are very accustomed to the current system, or who have had no prior access to or knowledge of services, may require more support, and take more time to adjust to the new ways of thinking and working that person centred planning will bring.

Research from the UK suggests that the information and training that was available to support the introduction of personalisation tended to focus on service providers, to the exclusion of people with disabilities and carers.^{vi} It is crucial that in NSW this situation is not repeated, particularly as research from the UK has also found that information is a precondition for choice, and that a lack of access to relevant information at the pre-choice stage can disadvantage individuals.^{vii}

Carers will be crucial stakeholders in person centred planning, and must be considered partners in the process alongside the person with a disability. Carers must therefore have access to similar information, training and support opportunities to support their engagement in person centred planning.

3.2.1 Training

Carers must have access to a range of training opportunities to enable them to engage effectively with the person centred planning process, delivered in various formats including face-to-face and online. The training needs of carers will vary considerably. Some of the key areas in which training should be developed and provided include:

- communication
- conflict resolution
- advocacy
- self-advocacy
- rights
- introduction to person centred approaches
- person centred planning.

Those individuals whose needs are not met by training provided to support person centredness should have access to funding to enable them to participate in other training

opportunities. This need may arise due to the particular skills that they need to develop, their geographic location, or issues relating to the accessibility of training in their area.

Training and resources which relate specifically to personalised funding are outlined in section 4.2.1.

Recommendation 5: Carers NSW recommends that carers be provided with access to the training they need to support their engagement in person centred planning, including training in communication, conflict resolution, rights, advocacy and person centred planning and approaches.

3.2.2 Information

Carers will need a wide range of information, in a variety of formats. The provision of information must take into account the diversity of the people who will require it. Information should be accessible to everybody regardless of their education or literacy level, geographic location, internet access, cultural or linguistic background, disability or other issue.

Information must be provided online, but there must also be other channels and other forms of information for those who do not or cannot access information online. Some opportunities for face-to-face delivery of information must be provided. For example, the opportunity to attend information sessions about the move towards person centred approaches and person centred planning must be provided.

Information relating to specific issues involved in person centred planning must be provided, in varying levels of details. Some carers will want detailed information, others will find an overview of key points more useful.

Carers will need information on topics such as:

- the role of carers in person centred planning
- carers rights in person centred planning
- accessing advocacy services
- dispute and resolution processes.

Recommendation 6: Carers NSW recommends that carers be provided with information online, face-to-face and through information sessions addressing the range of issues relating the role of the carer in person centred planning.

3.2.3 Sharing experiences and learnings

A crucial form of assistance will be the sharing of experiences between people involved in person centred approaches. For many carers, hearing about the experiences of others will prove invaluable to increase their confidence, assist them to understand person centred planning and to develop a fuller understanding of the range of possibilities open to them. It may help carers to avoid common pitfalls, as they will be able to learn from the experiences and mistakes of others.

A range of initiatives will be needed to facilitate a sharing of experiences between people, both carers and people with a disability. An online forum should be established, open to people involved in person centred approaches. This would allow people to interact and share their experiences, and for discussion threads to develop based on different issues. Such a forum would also be valuable to those involved in the provision of person centred planning or disability services, as they transition to new ways of working, and would inform the support they provide to people engaging with person centred approaches. The discussions that occurred in such a forum would also provide valuable insight to the NSW Government of the experiences of people engaging with person centred approaches.

People's experiences of person centred approaches should be published as case studies online, and in hard copy. This may be particularly important for those who are not familiar with the concepts of person centredness, or who do not understand how these concepts can be applied to their own situations.

Mentoring relationships between carers who have experience of person centred planning and other carers should be facilitated. Mentoring could occur through face-to-face contact, or through telephone or internet contact, depending on the circumstances and preferences of the individuals involved. Similar mentoring could be supported between people with a disability, staff involved in person centred planning, and also between families (including both the carer and the person with a disability in each family).

Recommendation 7: Carers NSW recommends that the sharing of person centred planning experiences be facilitated through the establishment of an online forum, the publication of case studies and the facilitation of mentoring relationships.

3.2.4 Other support, including support planners and intermediaries

Some carers may require considerable support to understand and engage with person centred planning, and to come to terms with its implications. Carers NSW experience of delivering the *Support Coordination Program for Older Parent Carers* and the *my plan, my choice: Individualised (Packaged) Support Participatory Action Research Strategy* (currently being undertaken by ADHC) is that some carers, particularly those who have been caring for long periods of time, need support to be able to make and exercise informed decisions. In the *my plan, my choice* pilot being conducted by Carers NSW the carer receives assistance from a support planner and a support intermediary. For many carers, similar or other assistance to plan and arrange support will be needed, and as such must be available for all carers if and when they require it. Some carers require quite intensive support, including counselling and coaching, for them to even begin thinking about planning for the future, or making changes to their current arrangements. Many carers also require additional support such as respite to be able to have time to prepare for and participate in planning sessions. Practical assistance such as transport should also be available to allow carers to participate in the planning process.

Recommendation 8: Carers NSW recommends that resources are allocated to provide carers with the support they need to engage in person centred planning, which may include support planners, intermediaries, counselling, respite and transport.

4. Personalised funding

4.1 Do you think individuals and their families and carers should have the option of managing a funding package themselves? Are there any circumstances where this is not appropriate?

Carers must have the option of managing a funding package themselves, however, it is crucial that it is their choice whether they manage a package or not. Self-management must be optional as many carers will not want this level of control, nor the associated work. Managing funding can be cumbersome, time and energy consuming and particularly difficult for older people who tend to be more cautious about managing their own care arrangements.^{viii} Evidence from the United Kingdom illustrates that carers supporting recipients of individual budgets were extensively involved in helping the consumer to use an individual budget, and in financial management and care coordination, and that the management of paperwork and on-going support arrangements generated more work for carers.^{ix}

Carers who do take up this option must also be able to opt out if and when they choose to. It is to be expected that some carers will try managing the funding package and decide that it is too much work, or too stressful. Others will find self-management beneficial for some years, but later decide that they no longer wish to exercise this level of control. For others, it may be a change in circumstance that leads them to opt in or out of self-management. A study by the University of York on disabled adults' and older people's experiences of making choices about services and support identified the tendency of individuals to move in and out of using direct payments, and to revisit their choices when circumstances change.^x

Carers NSW, whilst advocating that people be given the option of managing their own funding, recognises that there may be some cases in which this may be problematic. The capacity, past behaviours, or vulnerability of some individuals may give rise to serious doubts as to the wisdom of them taking on the management of their own funds. It is important in negotiating these situations that the principles of person centredness are foremost, that people's choices are respected, and that their confidence and capacity are not undermined. It is also important that people are able to make mistakes and take risks without losing the right to manage their own funding.

It is important to acknowledge that in many cases where self-management is not appropriate, the individual involved will not choose it. It should also be acknowledged that in those cases where the individual does choose to manage their own funding, there can be scope in the planning process to build in supports to assist them to manage the funding effectively, and to build in safeguards against known or likely risk factors.

For those cases where an individual is denied the opportunity to manage their own funding, it is important that the decision making process is transparent and well communicated, and that the person is able to dispute the decision through clear resolution processes, with the support of advocacy services if required.

Recommendation 9: Carers NSW recommends that carers have the choice of managing their own funding, and of opting out of managing their own funding.

Recommendation 10: Carers NSW recommends that transparent decision making processes are implemented and that decisions are clearly communicated to those affected.

4.2 What assistance and protections do you think people might need to direct and manage their own funding?

A variety of assistance should be made available to ensure that carers who choose to direct and manage their own funding are supported to do so. Assistance will be important to ensure that managing funding is not unnecessarily onerous or stressful, and to ensure that carers are not excluded from taking up this option if they lack the necessary skills. The following kinds of assistance must be available to anyone who chooses to manage their own funding, or is considering doing so.

4.2.1 Training

Carers must have access to training to develop the skills necessary for effective management of funds. This should include training in basic accounting, budgeting and computer skills. Online training modules should be developed and provided, as should face-to-face training.

Funding should be available for carers who have training needs that will not be met by the training that is provided. For example some carers, particularly those in rural areas, may not have access to face-to-face training in their local areas. In these instances, funding should be available to allow them to attend similar training provided through another institution, such as from a local community college, TAFE or other training provider. Some carers may need to develop skills that are not met by training provided for personalised funding. These individuals should be able to access funding for this purpose, if the skills in question will improve their capacity to manage and direct their own funding.

Training could build on existing services and resources, such as the Carers NSW *Connecting Carers to IT project*, funded by Ageing, Disability and Home Care. This pilot program will deliver basic IT training and support to carers in the community that are interested in learning how to access information, support and services on-line. This includes working with specific carer groups, including older carers.

Recommendation 11: Carers NSW recommends that carers be provided with access to the training they need to develop the skills to manage their own funds, including basic accounting, budgeting and computer skills.

4.2.2 Information

It is crucial that the information needed to direct and manage funding is available. As stated in section 3.2.2, it is important that a variety of formats and channels are used, and that face-to-face sessions about the introduction of personalised funding, and what managing one's own funding entails are available. Such information sessions should be held periodically, at

accessible venues around the state. For some carers, it will be important to be able to hear this information in person, have the opportunity to ask questions directly, and to hear the questions and comments of other participants.

Information about rights and responsibilities in managing funding, practicalities of managing funding, and about sources of training, support, advocacy and advice must be available and easily accessible. It should be proactively provided to carers. Carers' access to such information should not depend on them actively seeking it out.

Recommendation 12: Carers NSW recommends that carers be provided with information online, face-to-face and through information sessions addressing the range of issues relating to managing their own funds.

4.2.3 Resources

Resources should be provided to assist carers in the management of funding, including practical tools which can assist carers to manage funding effectively and ensure compliance with their responsibilities. Examples include

- templates for common purposes such as basic contracts, letters, and forms.
- check-lists to ensure that all steps have been taken or obligations met
- software to facilitate management of funding and appropriate record keeping.

In addition to information and resources, it is important that carers are able to access advice. This could be facilitated through the provision of a telephone hotline so that people can receive appropriate, timely, and informed answers to their specific questions. A comprehensive 'frequently asked questions' publication should be available online and in hard copy, updated frequently to reflect the issues and questions commonly recurring for people managing their own funding.

Recommendation 13: Carers NSW recommends that resources be provided to support carers to manage their own funding, including templates, check-lists, software and a hotline.

4.2.4 Sharing experiences and learnings

A crucial form of assistance will be facilitating the sharing of experiences between people, as discussed in section 3.2.3. As stated in the previous section, a range of initiatives will be needed to facilitate a sharing of experiences between people, including carers, people with a disability and people who work in the disability sector. This should include an online forum, the publication of people's experiences of personalised funding as case studies, and the facilitation of mentoring relationships.

4.3 How should the scope and size of funding packages be determined for individuals?

The scope and size of funding packages should be based on an assessment of the person with a disability, and when necessary, an assessment of the carer. Carer assessment will be necessary in many cases, and should be a common occurrence.

4.3.1 Assessment of the person with disability

Carers must be included in the assessment process of the person with a disability for whom they care, to a degree which reflects the level of their involvement in the care and support of that person. Their insight into the capacity and needs of the person with a disability should be respected. Although both parties should participate in the assessment process, it is also important that both the person with a disability and their carer have the opportunity to speak to the assessor without the other being present, to enable full and frank discussion of their needs and situation. Many people, both those with a disability and carers, would be less than frank in the presence of the other for a variety of reasons, including a desire to protect their feelings.

The assessment process must not make assumptions regarding what a carer can or will do. Carers must have choice in their caring role, and be given the opportunity to have choice and control in their own lives. That a carer will continue to provide care of the same nature or intensity as they did prior to assessment should not be taken for granted in future planning.

A proactive approach will be needed to ensure that carer assessment is a reality of the person centred system in NSW, as demonstrated by the experience of carers in the UK. Despite carer assessment being a legislated policy, a large scale study from the UK showed that no carer had an assessment of their own care related needs, and that the interface between individual budgets and carer assessment was poorly addressed. The quality of assessment practice which was inclusive of family needs was variable.^{xi}

Recommendation 14: Carers NSW recommends that carers are included in the assessment process of the person with a disability for whom they care, to a degree which reflects the level of their involvement in the care and support of that person.

4.3.2 Carer assessment

Carers should have the right to their own assessment, as individuals in their own right, with needs of their own. Carer assessment should take into account the carer's own life and priorities, their situation, the supports available to them, the impacts of their caring role, and their own health and wellbeing. The need for carer assessment has been recognised in the reports and recommendations of the Productivity Commission Inquiries into *Disability Care and Support*^{xii} and *Caring for Older Australians*.^{xiii}

Funding for carers to use for services and supports in their own right should be available, contingent on the results of a carer assessment. The allocation of funding to the carer should not come at a cost to the person they are caring for. Two separate packages would not

necessarily be required. To avoid increasing the management burden the funding could be allocated in the same package, with the carer's component quarantined or not, depending on the circumstances. However it is possible that in some cases two separate packages would be needed, or preferred, or that quarantining the funding for the carer would be necessary.

Recommendation 15: Carers NSW recommends that carers have the right to their own assessment as carers, and access to services and supports in their own right, when required.

A proactive approach will need to be taken to ensure that carer assessment occurs when needed, as demonstrated by the experience of carers in the UK, where carers have a legislated entitlement to assessment. According to Carers UK, half of those carers providing substantial amounts of care are unaware of their rights to assessment, and some are not even aware that they have been assessed.^{xiv} The failure of policies relating to carer assessment to be reflected in practice has also been demonstrated in the context of personalised services. A 2009 study on the impacts of individual budgets on carers raised concerns about the number of carer assessments occurring, as none of the carers taking part in the semi-structured interviews reported having a separate assessment of their own.^{xv} This study also found considerable variation in practice and attitudes towards carers in different individual budget pilots, and amongst individuals.

To ensure that carer assessment is a reality, and that it occurs when necessary, a proactive approach will be needed. Carer awareness training for assessors and information and education for carers (to ensure they are aware of the possibility of their own assessment) will be important. Consideration must also be given to monitoring the number of carer assessments occurring to ensure that they are being taken up at appropriate levels.

Recommendation 16: Carers NSW recommends that the implementation of carer assessments is supported by carer awareness training for assessors, and by the provision of education and information to carers.

Recommendation 17: Carers NSW recommends that the prevalence of carer assessment be monitored to ensure appropriate uptake.

4.3.3 Reassessment

Carers, as well as people with a disability, must have the right to request assessment, and to request reassessment when their needs or situation changes. Reassessment of both the person with a disability and of the carer should occur periodically, and should be triggered by significant transition points or changes. For example, reassessment should be triggered by a person finishing education, moving out of home, marrying or divorcing. Changes, such as a deterioration in health or wellbeing, should also trigger reassessment.

Recommendation 18: Carers NSW recommends that carers have the right to request reassessment of themselves, or of the person with a disability.

Recommendation 19: Carers NSW recommends that reassessment be triggered by significant transition points or changed circumstances.

4.3.4 Dispute processes and supports

There must be clear pathways and supports in place to enable people to challenge the results of their assessment. Provisions must be made to ensure that when an assessment is challenged, a fair process occurs, and that there is some independent review of the assessment and its findings. Advocacy services for carers will be integral to providing carers with the support that they need to be able to undertake a dispute process.

Carers should be able to both challenge the results of the assessment on behalf of the person they care for (when appropriate), or to challenge the results in their own right as a carer. This is vital given that shortcomings in the assessment process or resulting package will often negatively impact on the carer as well as on the person with a disability. In some cases, the impacts on the carer can be highly significant and long term. For a carer, an inadequate funding package may lead to serious negative impacts on their health and wellbeing, withdrawal from education or employment, and neglect of other responsibilities, including to other family members. Equally, carers must also be able to challenge the results of their own assessment.

Recommendation 20: Carers NSW recommends that carers have access to transparent and clear resolution processes in the case of a disputed assessment.

5. Moving to a person centred system

5.1 What assistance will providers need to manage the transition?

It is important that the assistance provided to providers emphasises the importance of complying with the *Carers (Recognition) Act 2010* and the need to recognise, include and work with carers in a person centred system. The information, guidelines, training and other assistance and direction given to providers in the transition to person centred approaches must establish robust practices of carer recognition and inclusion, and create a culture of carer inclusiveness, and a person centred system which has the individual *and* their carer and family at its centre.

Carers NSW is all too familiar with the propensity for legislative and policy changes relating to carer recognition and inclusion to fail to translate to real cultural and practical change on the ground. With the introduction of person centredness, which will fundamentally change the way in which the disability sector exists and operates, a rare opportunity presents itself to create real change for carers. The NSW Government must ensure that carers are recognised, included and supported in every aspect of the creation of a person centred system, and that the assistance and direction provided to service providers ensures that carer recognition and inclusion is at the heart of this transformation, and is not treated as an afterthought or optional add-on to person centred approaches.

Recommendation 21: Carers NSW recommends that assistance and direction given to providers in the transition to a person centred system support the systematic recognition, inclusion and support of carers.

6. Conclusion

Carers NSW appreciates the opportunity to provide a submission to the person centred approaches consultation. The introduction of person centred approaches provides a rare opportunity to transform the lives of carers and to make the principles of the *NSW Carers Charter* a reality in the disability service system in NSW.

Carers NSW looks forward to supporting the introduction of person centred approaches, and is available to provide advice and support to the process to ensure that the result of this reform is a system which truly has people with a disability and their carer and family at its centre. Carers NSW is optimistic that the introduction of person centred approaches will finally allow carers to live life their way.

End notes

- ⁱ NSW Legislation, Carers (Recognition) Act 2010 [online], Accessed at: <http://www.legislation.nsw.gov.au/fullhtml/inforce/act+20+2010+cd+0+N>, Sydney, 2010.
- ⁱⁱ H Sanderson, *Person Centred Planning: Key Features and Approaches*, Joseph Rowntree Foundation, London, 2000.
- ⁱⁱⁱ C Glendinning et al, *The Individual Budgets Pilot Projects: Impacts and Outcomes for Carers*, Social Policy Research Unit, University of York and Personal Social Services Research Unit, University of Kent, 2009.
- ^{iv} Ibid
- ^v H Sanderson, *Person Centred Planning: Key Features and Approaches*, Joseph Rowntree Foundation, London, 2000.
- ^{vi} S Dowling et al, *Person-centred planning in social care: A scoping review*, Joseph Rowntree Foundation, London, 2006.
- ^{vii} K Baxter, P Rabiee and C Glendinning, *Choice and change: disabled adults' and older people's experiences of making choices about services and support*, Social Policy Research Unit, University of York, York, 2011.
- ^{viii} The Winston Churchill Memorial Trust of Australia, *The Vincent Fairfax Churchill Fellowship to investigate "consumer-directed" aged care policy and practice*, Report by Ian Hardy 2008 Churchill Fellow, accessed at: http://www.churchilltrust.com.au/site_media/fellows/HARDY_Ian_2008.pdf, 2008.
- ^{ix} C Glendinning et al, *The Individual Budgets Pilot Projects: Impacts and Outcomes for Carers*, Social Policy Research Unit, University of York and Personal Social Services Research Unit, University of Kent, 2009.
- ^x K Baxter, P Rabiee and C Glendinning, *Choice and change: disabled adults' and older people's experiences of making choices about services and support*, Social Policy Research Unit, University of York, York, 2011.
- ^{xi} Ibid
- ^{xii} Productivity Commission, *Caring for Older Australians*, Report No. 53, Final Inquiry Report, Canberra, 2011.
- ^{xiii} Productivity Commission 2011, *Disability Care and Support*, Report no. 54, Final Inquiry Report, Canberra, 2011.
- ^{xiv} Carers UK, *Missed Opportunities; The Impact of Carers' New Rights*, London, 2003.
- ^{xv} C Glendinning et al, *The Individual Budgets Pilot Projects: Impacts and Outcomes for Carers*, Social Policy Research Unit, University of York and Personal Social Services Research Unit, University of Kent, 2009.