NCOSS Discussion Paper:

Get this party started: Why we need Person Centred Approaches in NSW Community Care

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Council of Social Service of NSW (NCOSS)
66 Albion Street
Surry Hills NSW 2010
Ph: 02 9211 2599
Fax: 02 9281 1968
Email: info@ncoss.org.au

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 social, systemic and operational issues.

NCOSS membership is composed of community organisations and interested individuals. Affiliate members include local government councils, business organisations and Government agencies.

Member organisations are diverse, including unfunded self-help groups, children's services, youth services, disability service providers, emergency relief agencies, chronic illness and community care organisations, family support agencies, housing and homeless services, mental health, alcohol and other drug organisations, local Indigenous community organisations, faith-based groups, peak organisations and a range of population-specific consumer advocacy agencies.

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Introduction

The community care sector in NSW is undergoing considerable transformations. As well as the *National Health Reform Agreement* signed by the Council of Australian Governments (COAG) in 2011, the disability and aged care sectors are undergoing reforms which will have profound implications for the community care sector.

The *National Health Reform Agreement 2011* divides responsibility for the Home and Community Care (HACC) Program between State and Commonwealth Governments on the basis of age, with State Governments maintaining responsibility for services for younger people with disability (non-Aboriginal people under 65 and Aboriginal and Torres Strait Islander people under 50), and the Commonwealth assuming responsibility for older people. In NSW the former HACC Program for younger people with disability has been renamed the Community Care Supports Program (CCSP).

Stronger Together: A new direction for disability services in NSW 2006-2016 is the plan that underpins the transformations to the disability sector in NSW. Under Stronger Together 2, people with disability using services funded by the NSW Government under the National Disability Agreement (specialist disability services) will be able to convert the value of those services into a portable, individualised arrangement from 1 July 2014. This change is part of a wider reform agenda to implement person centred approaches in disability services in NSW, which NCOSS strongly supports.

NSW is undertaking these reforms with a view to implementing the National Disability Insurance Scheme (NDIS) within NSW from 2016. Government agreements to implement the NDIS will transfer funds currently allocated to the CCSP to the NDIS.

In the context of these reforms, it is important that the community care sector is not left behind. Reforms to disability must take into account the people who require community care style supports, and the community care sector must be supported to take advantage of the opportunities that these reforms will bring about.

The purpose of this paper is to state why, in NCOSS' view, **all** NSW Government-funded supports used by people with disability in NSW should be able to be converted to portable individualised packages. NCOSS maintains that this option should be available to people using services funded under the CCSP, or community care services.

NCOSS believes a policy agenda supporting person centred approaches is able to be fully implemented in community care. This paper sets out the context for this reform, discusses some statistical data relating to the approximately 50,000 younger people with disability using community care services, and states what needs to occur in the sector in order to implement person centred approaches successfully.

The *National Health Reform Agreement* specifies that no significant changes will be made to service delivery mechanisms funded under the HACC Program until 1 July 2015. NCOSS considers that the option to convert to a portable, individualised funding arrangement ought to be implemented for people using community care services from 1 July 2015 at the latest. It would be preferable for all people with disability using supports funded by the NSW Government to have the same option – to convert the value of their government funded support into a portable, individualised arrangement – at the same time, from 1 July 2014, to ensure that implementation is fair and consistent.

However, individualised funding mechanisms are not the only elements of person centred approaches that should be put into effect in NSW. Central to a person centred approach is support for meeting objectives identified by the person themselves. These objectives relate to a person's life, rather than service provision. Through meeting these objectives, the participation of people with disability in community life can be enhanced and, in some cases, this will reduce the amount of funded support required.

Traditional approaches to disability support have involved block funding to service providers, and those service providers then making choices about how peoples' lives would be led. Person centred approaches emerged in the disability sector because block funding did not deliver the best outcomes for many people. Disability advocates sought to emphasise the human rights of people with disability to direct their own lives in the ways they choose, using support to give people with disability better life opportunities.

Person centred approaches treat the aspirations, strengths and skills of the person as the meaningful starting point for planning support. Where traditional approaches have focused on compensating deficits, person centred approaches focus on putting supports in place to enable a wider range of life choices.

The community care sector has a number of strengths that can enhance person centred approaches, and lessons which can be shared with the specialist disability sector.

Summary of recommendations

1. That ADHC carry out targeted consultations with younger people with disability to determine how best to facilitate access to person centred support.
2. That ADHC undertake an inclusive planning process, including consultation with people with disability in Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities.
3. That the NSW Government allocates ongoing growth funds to ensure that funding allocations meet the identified needs of people with disability needing basic community care supports.
4. That ADHC ensure that regulation and accountability requirements enable people with disability to use funds flexibly and creatively.
5. That ADHC support capacity building for people with disability through consultation, allocating specific funds, and promoting resources on working with person centred approaches.
6. That ADHC fund advocacy, counselling, information, interpreters, and carer support separately from funding for individual support packages.
7. That ADHC allocates funds to build the capacity of HACC/CCSP service providers to work effectively with person centred approaches.

Background: the HACC Split and the NDIS

The HACC Split

The Home and Community Care (HACC) Program has been operating since 1985, with many services now funded through the HACC Program operating from much earlier. Services that became part of the HACC Program arose from localised initiatives that people began in their local communities, such as local volunteer Meals on Wheels and neighbour aid services. Since its inception, the HACC Program has been jointly funded by the Commonwealth and State Governments.

In the 2011 *National Health Reform Agreement*, the Commonwealth and State and Territory Governments (excluding Victoria and Western Australia) agreed to a division of responsibilities for care and support services for older people and people with disability. The Commonwealth Government assumed sole responsibility for funding and policy relating to care and support services for non-Aboriginal people aged 65 and over, and Aboriginal and Torres Strait Islander people aged 50 years and over. State and Territory Governments maintained sole responsibility for funding and policy relating to care and support services for non-Aboriginal people aged under 65 years, and Aboriginal and Torres Strait Islander people aged under 50 years. In 2012, new contracting arrangements were put in place, with a number of community care providers entering funding agreements with both levels of government.

This paper relates to the component of the former HACC Program for younger people with disability, funded and administered by the NSW Government, Department of Family and Community Services, Division of Ageing, Disability and Home Care (ADHC), which has been renamed the Community Care Supports Program (CCSP).[1]

National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) involves nationwide reform to disability support.[2] The proposed model of the NDIS would provide an individualised support package of funding for people with disability who needed funded supports.

The NSW Government has negotiated with the Commonwealth to implement the full NDIS throughout the State from July 2016, with full roll-out by July 2018. Funds for disability and community care services will be transferred to the NDIS. The *Heads of Agreement between the Commonwealth and NSW Governments on the National Disability Insurance Scheme*, signed in December 2012, and the *Intergovernmental Agreement on the National Disability Insurance Scheme Launch* specify that funding for community care services will be transferred to the NDIS.[3]

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[1] See ADHC (2012) *Guidelines for NSW Community Care Supports Program*, Sydney, October.

[2] See Commonwealth of Australia (2012) *National Disability Insurance Scheme*, Canberra, at: http://www.ndis.gov.au/ (last accessed: 08/11/2012).

[3] See NSW Government (2012) *Heads of Agreement between the Commonwealth and NSW Governments on the National Disability Insurance Scheme*, available at: http://www.nsw.gov.au/ndis (last accessed: 25/02/2013) clause 33, which specifies that "[f]ollowing commencement of the full NDIS, the NSW Government will not provide any residual specialist disability services or basic community care services."
See COAG (2012) *Intergovernmental Agreement on the National Disability Insurance Scheme Launch*, Canberra, available at: http://www.coag.gov.au/node/485 (last accessed: 25/02/2013), clause 56, which specifies that "a proportion of Commonwealth funding from the National Disability SPP (NSPP) and payments made under the National Partnership on Transitioning Responsibilities for Aged Care and Disability Services and the Home and Community Care Agreement will be contributed to the Agency by

The NSW Government is specifically planning its reform initiatives relating to specialist disability services to align with the NDIS. A number of people using community care services will be eligible for support under an NDIS. However, there have been no reform initiatives announced as yet that will apply to community care, or support the community care sector to transition to the NDIS.

It is also not clear whether the target group for the CCSP will meet the eligibility criteria for the NDIS, despite funding for community care for younger people with disability being transferred to the NDIS.

Why we need Person Centred Approaches now

NCOSS supports the introduction of person centred approaches, including individualised/self-directed funding, in community care for younger people with disability currently using HACC/CCSP services. For many people currently using HACC services, this will involve most of the same kinds of mechanisms as are available to people using specialist disability services. For others, it may require new types of funding, governance and policy mechanisms to implement person centred approaches successfully.

Choice & control

Community care services have always largely been block funded. Community care services have also grown from local initiatives that were very locally responsive, to a program that is more driven by output requirements, service categories, and data classifications.

Community care services can play a key enabling role in people's lives that allow people to remain independent, access mainstream opportunities and activities in the community, and enjoy a quality of life they otherwise may not be able to. Despite the fact that many community care services are of a lower intensity, and do not have as encompassing an effect on a person's life as many specialist disability services, however, choice and control for people in how services are delivered remains vital for leading good lives. Social participation and inclusion of people with disability needs to be underpinned by community care support that is flexible according to a person's choices, preferences and requirements, whereas traditional approaches expect a person with disability to fit into the requirements of the service system. Traditional approaches have tended to mean that many people with disability have missed out on opportunities and activities they might have otherwise accessed.

The introduction of person centred approaches and self-directed support for people using community care is therefore likely to result in more age-appropriate outcomes for people with disability. People with disability who are employed, have children or engage in other activities that the majority target group for the former HACC Program – frail older people – were less likely to engage in, such as attending a wedding, or seeing a friend's band perform in the evening, would be able to use self-directed funding to facilitate these life-enhancing activities.

People with disability will be able to access a broader scope of choices in how they arrange their supports, including accessing support outside of the service system e.g. employing a friend or family member to provide personal care, or purchasing

host jurisdictions on behalf of the Commonwealth to meet part of the Commonwealth contribution to the cost of an NDIS in launch sites."

mainstream equipment. Person centred approaches could also assist Aboriginal people with meeting cultural obligations such as returning to country.[4]

Sofie's Story: Failure of flexibility*

Sofie is a 41 year old person in a wheelchair who has a full time job that requires some work outside 9-5 hours on weekdays. Despite being a long term client of an organisation that also provides community care packages (CACPs and EACH) outside business hours, she has been told that the latest time a HACC fieldworker is available to provide domestic assistance is 3:45 pm on a weekday. Although it was offered as an alternative, Sofie can't accommodate a morning service within her pre-work schedule. She has offered to pay extra for a weekend service, but the HACC Co-ordinator said her organisation will not permit that. Private, non-HACC alternatives are $41/hr+ (3 times what she pays for HACC), and require a minimum 2hr booking. Instead, Sofie has to go home early each fortnight for her domestic assistance service, and often cancels due to work commitments; the HACC provider is very understanding, and always offers a re-scheduled service, but Sofie's work schedule rarely allows for that. If the unwashed floors become a hazard in the interim, Sofie's 68 year old mother comes to Sofie's house and cleans.

How could a person centred approach result in a better outcome?
Sofie would be able to access services on days and times that suit her, such as after 6 pm on weekdays, or Saturdays. This would also remove the need for family back-up when services cannot arrange to provide support.

* Name changed to protect the identity of the person

Under the current HACC/CCSP system, people are locked into service delivery types and patterns, with no flexibility for occasional changes in need without a re-assessment, which generally has a delay beyond the period of need. Implementation of person centred approaches would allow for greater timeliness, responsiveness and seamlessness for people with disability.

Peta's Story: A quicker response*

Peta, a person in a wheelchair, is able to live independently with only the support of a fortnightly domestic assistance service, occasional community transport and supports from ageing parents. However, when flu strikes once a year, Peta becomes very frail and sometimes wants some additional assistance, such as Meals on Wheels for a week or so instead of the domestic assistance. Likewise, if the parents are ill & unable to visit or go on holidays, Peta may need/want to access a 24-hour on-call service for emergencies, such as falls (such as EACH & NRCP clients currently receive).

How could a person centred approach result in a better outcome?
Peta could alter the usage/purchasing patterns within the allocated budget.

* Name changed to protect the identity of the person

[4] See NSW Aboriginal Community Care Gathering Committee (2012) *Challenge, Change & Choice Policy Position*, Sydney, available at: http://ncoss.org.au/resources/120704-challenge-change-choice.pdf (last accessed: 04/03/2013).

Participation & inclusion

Person centred approaches are focused on the dignity, rights, and participation of people with disability in community life, whereas community care has more traditionally focused on preventing premature institutionalisation/residential care. A person centred approach would be more effective at improving as well as maintaining life. A focus on holistic objectives, set by people with disability, can be as effective at preventing premature institutionalisation, and more effective at ensuring sustainable social participation, as traditional approaches.

For instance, the Victorian Auditor-General found that Individual Support Packages gave people the opportunity to live independently and develop life skills.[5] Likewise, the UK National Audit Office found that people using personal budgets reported improved independence and wellbeing.[6]

It is likely that, in the future, people with disability in NSW who would be eligible for CCSP/HACC funded supports will have access to a person centred approach through the Ability Links Program.[7] The Ability Links Program is intended to be an access point for support in NSW for people with disability, with a community development focus. Ability Links co-ordinators will support people to access or make use of both funded and unfunded resources. The Ability Links Program prioritises accessing mainstream community and personal resources before seeking funded support for a person. Without implementation of person centred approaches in community care, it is likely that people with disability currently in the service system will have fewer opportunities compared with those seeking support at a later time. Implementation of person centred approaches is necessary to ensure that all people with disability can have access to enhanced opportunities.

Fairness & consistency

There will be a significant number of people using community care services who will expect to be able to convert the value of services they use to an individualised arrangement. Many people using community care services in NSW participated in the *Living Life My Way* consultations that took place over 2011 and 2012. Others will have some familiarity with the implementation process for person centred approaches in disability support in NSW, or with the NDIS. For these people, it is not fair to expect them to be limited by bureaucratic program boundaries, when people in similar circumstances using specialist disability services are able to convert their service to an individualised funding arrangement.

Most people with disability using services do not identify with the bureaucratic boundaries that governments use to allocate funds. Implementing person centred approaches in community care will bring community care services into line with other services for people with disability in NSW. People using community care should not be subject to restrictions that other people with disability using funded services do not face. Consistency is particularly important where people currently using HACC services will be under an NDIS.

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[5] Victorian Auditor-General (2011) *Individualised Funding for Disability Services*, Victorian Auditor-General's Office, September, pp. 16-17.

[6] Auditor-General (2011) *Oversight of user choice and provider competition in care markets*, National Audit Office, London, September, pp. 18-19.

[7] See ADHC (2012) *Ability Links NSW*, Sydney, available at: http://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/ability_links_nsw, last updated: 21/12/2012.

Creating incentives

After the division of the former HACC Program in July 2012, there were reports from across NSW that younger people with disability had access to community care services restricted. Some NSW and Commonwealth Government officers advised non-government service providers that they must maintain their client numbers according to the division of their contracts by age group. Consequently, non-government service providers, according to reports received by NCOSS, restricted the numbers of clients they accepted on the basis of age.

Since younger people with disability are the minority target age group for the Commonwealth HACC Program/NSW CCSP, and the NSW Government is the minority funder for many community care providers, there are clear disincentives for service providers to work with younger people with disability. Furthermore, as growth funding is guaranteed in Budget Forward Estimates for the Federal Budget for the Commonwealth HACC Program for older people, there is greater incentive for community care service providers to specialise in working with older people than with younger people with disability.

Implementation of self-directed support and person centred approaches would allow people with disability a broader scope of choice in which supports they use and how those supports are delivered. It would also create incentives for other service providers to find ways to service the market that would emerge.

Building on strengths

Introduction of person centred approaches would not necessarily mean that community care providers would have to change their practice totally. Many service providers have wanted to work more flexibly, but have not been able to do so because of limitations in current funding arrangements, guidelines and other requirements. Implementing a person centred approach would allow providers currently involved in community care to build on their strengths, particularly their local responsiveness and community base.

Aboriginal workers and service providers particularly have been working in holistic and responsive ways for a considerable time. NSW initiatives such as the Aboriginal Access and Development Officer program under HACC/CCSP have also played an important part in supporting community development activities, and facilitating alternative methods of community engagement, e.g. Elders' Olympics, which have an important social aspect, as well as promoting health and wellbeing, and strengthening links between Aboriginal communities and the broader community care sector.

Community care in NSW has a number of strengths that the disability sector could benefit from, such as access to interpreters, access to counselling and carer support, and supported access to services. Innovative practice, such as Enablement[8], could be further enhanced by implementing a person centred and self-directed approach. Lessons and skills from the community care sector could enhance practice in the disability sector by allowing workers to work with a broader range of clients, and building on workers' existing knowledge and networks.

Starting early

The reform timetable for disability supports is rapid, involving building a range of new resources, including access points, local area co-ordination, and decision support

[8] See the IMPACT NSW website at http://impactnsw.com/ (last accessed: 12/11/2012).

resources between 2014 and 2016.[9] If the CCSP and people with disability reliant on community care are not considered in these initiatives, disability reform initiatives may not be appropriate for people using community care services.

As other States and Territories are also committed to transferring funds for community care programs for people with disability to the NDIS, NSW has the opportunity to take leadership in this area, and inform changes in other parts of Australia.

A person centred approach: What needs to happen?

For all stakeholders

Clear information

All stakeholders in community care services need to have clarity about the circumstances of the people with disability using community care, and details about services to this age group. Publication of information already held in the Minimum Data Set would be valuable for planning how to implement person centred approaches for the CCSP target population:

- Number of people using each CCSP service type, broken down by Aboriginal and/or Torres Strait Islander status, cultural and linguistic diversity, region, remoteness, proportion relying on government income support, employment status, carer status, disability or condition causing functional limitation;
- Number of people using multiple services; and
- Health circumstances, such as chronic illness, mental illness, or other health conditions.

Other information, which has been collected at various times, would be valuable to update, although transition to person centred approaches should not be delayed through investigating these matters:

- Other circumstances such as availability of carers, number of people living in boarding houses or other precarious accommodation;
- Data on the nature of service provision for younger people with disability such as different hours of operation to suit the age group; and
- Unmet needs for the target population.

Clarity on these data is important to ensure that any changes to the CCSP address the needs of the target population effectively. This information will help stakeholders to decide how person centred approaches will be implemented best for the target population. This information will form the basis for planning about specific support and access mechanisms for particular population groups, moving to more age appropriate support, and the range of supports that are likely to be resourced under a person centred approach.

People with disability, carers, families, service providers and other stakeholders will need clear information from ADHC about how changes will be implemented, and how they can participate in the process.

[9] ADHC (2012) *Putting people with disability at the centre of decision making: Outcomes of statewide consultations May – August 2012*, Sydney, available at: http://www.adhc.nsw.gov.au/about_us/strategies/person_centred_approach/person_centred_approaches_consultations (last accessed: 25/02/2013), see chapters 2-3, and Appendix 1.

Genuine engagement of people with disability and their carers and families

Engagement between government and the community will need to involve the development of genuine trust. Person centred approaches involve people with disability making decisions as experts in their own lives, so engagement will need to be approached with the goal of establishing genuine collaboration and partnership between government and people with disability. Consultation will need to be proactive, to allow participants the time to give genuine feedback on the issues of concern, with adequate preparation. Each community may require different methods of engagement, so that all members of the community have the opportunity to have input into local processes. A feedback loop should be established, to demonstrate how input has been considered and taken into account in planning and policy development. Ongoing processes of engagement and participation need to be established to ensure that arrangements around making disability support available continue to meet the needs of the community.

Recommendation 1

That ADHC carry out targeted consultations with younger people with disability to determine how best to facilitate access to person centred support.

Open and robust dialogue

Clear information is an essential prerequisite for a high quality dialogue between stakeholders on what is necessary to successfully implement person centred approaches and individualised funding.

Planning

Clear plans for implementation must take the breadth of factors into account. Planning for support for population groups who are disadvantaged in accessing community care services, such as Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse communities must be included from the beginning. Access mechanisms, decision support resources, and other initiatives to support person centred decision making must be accessible, appropriate, and available to all people in the target population from the outset.

Recommendation 2

That ADHC undertake an inclusive planning process, including consultation with people with disability in Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities.

Adequate funding and growth

Funding allocations will need to continue to grow annually to address the unmet and under-met need in the community, and as the target population grows. Government must allow for appropriate allocations of funds to meet the identified needs of people with disability.

Recommendation 3

That the NSW Government allocates ongoing growth funds to ensure that funding allocations meet the identified needs of people with disability needing basic community care supports.

Appropriate levels of regulation and accountability

All stakeholders in community care will benefit from appropriate regulation, quality assurance, data collection and accountability requirements that allow people with disability to make the best possible decisions, while not being overly burdensome or a deterrent to using funds flexibly. People with disability must be able to take reasonable risks, and to change their minds about how they use services if they wish.

While lifestyle planning in specialist disability services may be appropriate, such a comprehensive level of planning for people using community care services may not be appropriate. Personal planning, accountability and quality requirements must not be a barrier to a person accessing support. Some people may only need one service and may not require intensive planning to use it.

Recommendation 4

That ADHC ensure that regulation and accountability requirements enable people with disability to use funds flexibly and creatively.

Community development

Not all activities and supports necessary to ensure a good quality of life for people with disability will be able to be supported through individualised funding. Support for community development is an important aspect of promoting access to services, as well as social inclusion, health promotion, and community connections. Block funded initiatives such as the roles of Aboriginal HACC Access and Development Officers, Multicultural Access Project Officers, and community events will need to continue to be funded, though they may have a different emphasis under a person centred approach. These are particularly important in Aboriginal communities, where there are often a lack of resources within the community, and a lack of funding opportunities from outside funders.

Recommendation 5

That ADHC continue to block-fund community development activities, particularly for Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities, and for socially disadvantaged communities. These activities and roles need to have consistent coverage across NSW.

Consumer safeguards

Consumer safeguards need to be built into person centred disability support, to ensure that funds are used effectively. A framework for transparency in spending, which is in Easy English, needs to be established to ensure that service providers are genuinely accountable to people with disability. This will be especially important for people who have not had opportunities to develop financial management skills.

Recommendation 6

That ADHC implement a framework for transparency in the use of individual disability support packages in plain English.

Innovative and flexible thinking

For person centred approaches to be successful in community care, people with disability, families, carers, service providers, government and other stakeholders will need to be open to new possibilities outside the current service system framework. Information (including in Easy English), presented in a variety of ways, that showcases the potential options and outcomes of person centred approaches can facilitate this.

For people with disability, their families and carers

Access mechanisms that are equitable and culturally responsive

Mechanisms to access person centred support must be inclusive of people in a variety of circumstances. People without strong support networks, carers who can advocate on their behalf, or the knowledge and skills to manage their supports will also need to be able to access support. A variety of methods for disseminating information, screening for eligibility, assessment and allocating support resources need to be established, to ensure that socially disadvantaged people can access necessary support. Assessment tools need to be sensitive of those without significant personal resources to supplement government funds. Access mechanisms also need to be able to address sensitivities around accessing support, particularly the shame and stigma. Access mechanisms will ensure that disability supports are allocated effectively and can prevent crises.

Independent information, advice and capacity building

Independent information and advice will be needed to inform people to be able to exercise choice. For some, these needs will be significant, and may involve support for life planning, capacity building or training. Some people may need decision support resources, and others only basic information. Some block funding may need to be allocated for these supports. NCOSS recommends that specific resources are made available for Aboriginal people to develop plans and build capacity to engage with individualised funding packages.

Recommendation 7

That ADHC support capacity building for people with disability through consultation, allocating specific funds, and promoting resources on working with person centred approaches. Specific resources should be made available for Aboriginal people.

Independent advocacy

Individual and systemic advocacy for people with disability should be funded separately from support packages. A person should not have to pay for the cost of an occasional need for advocacy from funding for ongoing support expenses. Separate advocacy for carers needs to also be funded to ensure that both people with disability and carers have access to appropriate support.

Advocacy for Aboriginal people needs to be culturally appropriate, as there are significant barriers to Aboriginal people with disability accessing support. Advocacy can build the capacity of Aboriginal communities to work with person centred disability support through resolving systemic issues, finding creative solutions, and providing safeguards.

Specialised supports

Specialised projects and activities currently funded under the Commonwealth HACC Program/NSW CCSP that engage in community development and support access to services, such as counselling and advice for carers, bilingual workers, and Dementia Advisory Services should continue. These supports should be funded separately from the support packages for people with disability, and may need to be block funded.

Access to interpreters

People with disability and/or their carers and families should be able to continue to access interpreters without this access reducing their individual budgets. Interpreting services may also need to remain block funded.

Recommendation 8

That ADHC fund advocacy, counselling, information, interpreters, and carer support separately from funding for individual support packages.

Technical and financial supports

These could be financial intermediaries, or tools to manage funds, ensure accountability, address industrial obligations, and report on outcomes. Specialised technical and financial support needs to be available that addresses cultural issues which may act as a barrier to support. For instance, there is considerable stigma around seeking assistance with financial matters for Aboriginal and Torres Strait Islander communities. Technical and financial support will need to be closely connected to communities to be responsive to these issues.

Genuine choice

NCOSS supports the existence of a viable and vibrant service sector. People with disability deserve to be able to make genuine choices from a range of options, regardless of their cultural background, their geographic location, or socio-economic status. At present there is a lack of culturally appropriate service in regional areas, and in some areas there is only a single provider of a service type. Block funding may need to occur for some support to ensure that viable options are available, especially for services for particular population groups such as Aboriginal people, or for sustainable service activities in regional and remote areas.

For service providers

Capacity building

The service sector will need to develop its capacity to deliver services along person centred lines. ADHC will need to support innovation and new approaches among the service system. While the Industry Development Fund (IDF) has been allocated to support specialist disability services to adapt to implement person centred approaches, HACC/CCSP service providers have been de-prioritised for access to IDF funded activities.

Recommendation 9

That ADHC allocates funds to build the capacity of HACC/CCSP service providers to work effectively with person centred approaches.

Younger people with disability using community care

In NSW, there are around 50,000 people in NSW under the age of 65 who currently use Home and Community Care (HACC) supports due to their functional disability.[10] This number is similar to the number of people in NSW using specialist disability services administered by the NSW Government.[11] These are the people who would benefit from putting person centred approaches into place in community care services in NSW.

Data supplied by ADHC to NCOSS shows that people under 65/50 using community care services in NSW are diverse in their use of services, their needs, their types of disability, and their patterns of service use. A significant number of this cohort is aged 55-64 years.

A little over 25,000 among these 50,000 people use very low levels of service, of less than 1 hour per week, on average. However, the younger HACC client group also incorporates the High Need Pool, which includes people with disability who need significant physical support of 15-35 hours per week. Approximately 10,000 people using HACC services also use specialist disability services.

Among the younger HACC client group are numerous people with complex needs, including significant personal care needs, neurodegenerative disorders, intellectual disability, mental health conditions, people living in boarding houses, people with chronic health conditions (more common among Aboriginal and Torres Strait Islander people), people with younger onset dementia, as well as children and young adults with significant physical support needs. A joint ADHC and NSW Health project also recently revealed that a number of younger people using HACC services had a high rate of repeated hospitalisation and emergency department presentations.

On average, younger people with disability use a greater amount of community care services per capita, particularly for some service types, than people aged 65 and over. Home modification, case management, respite and personal care are some of the service types where younger people use significantly more per capita than older people.[12]

There are a number of people who only use one service type, often transport, meals or respite. Some of these instances of service complement peoples' use of other services, including specialist disability services, or, for example, community transport services being used to access health services.

There are a small number of people, about 3,000, who have very high needs; around 40% of this group also uses specialist disability services. There is higher correlation of use of specialist disability support with higher use of HACC services.

6% of younger people with disability using community care services are Aboriginal and 9% are from culturally and linguistically diverse communities. Further information is needed to determine how this proportion compares with the number of Aboriginal

[10] Australian Government Department of Health and Ageing (2011) *Home and Community Care Program Minimum Data Set 2009-10 Annual Bulletin*, Australian Government Department of Health and Ageing, Canberra, Table A3.
[11] Steering Committee for the Review of Government Service Provision (2012) *Report on Government Services 2012*, Productivity Commission, Canberra, Table 14A.13.
[12] Australian Government Department of Health and Ageing (2011) *Home and Community Care Program Minimum Data Set 2009-10 Annual Bulletin*, Australian Government Department of Health and Ageing, Canberra, Table A20.

and Torres Strait Islander people and people from culturally and linguistically diverse communities are in the target population.

Context: disability and aged care reform

The disability and aged care reform agendas involves comprehensive changes to both sectors. Community care services are in many ways caught between the two reform processes, and have not been fully incorporated into either process. Both reform processes will have significant effects on HACC/CCSP service providers.

Stronger Together 2

Disability services in NSW are undergoing a process of reform under the *Stronger Together: A new direction for disability services in NSW 2006-2016* plan. The second phase of the plan (*Stronger Together 2: 2011-2016*) involves major reforms to the funding and policy mechanisms governing disability services in NSW.

Most significantly, *Stronger Together 2* involves funding reform that would allow people with disability to access individualised portable funding, providing choice and control over the supports they need. From 1 July 2014, people with disability using specialist disability services will be able to convert the value of the services they use into a portable, individualised funding arrangement.[13]

Stronger Together 2 also involves initiatives that would support people with disability to make decisions about how to use funds allocated for them, resources to help people manage those funds, and mechanisms to facilitate access to support resources.[14]

Reforms to community care services for people with disability are not included in the *Stronger Together 2* plans.

National Disability Insurance Scheme

The NDIS involves nationwide reform to disability services.[15] The proposed model of the NDIS would provide an individualised support package of funding for people with disability who needed funded supports.

The NDIS will be launched in five specific sites across the country. NSW has also negotiated with the Commonwealth to implement the NDIS throughout the state from July 2018. In NSW, the launch site is located in the Hunter region (involving the Newcastle, Lake Macquarie and Maitland Local Government Areas), and will involve around 10,000 people. It is planned to begin on 1st July 2013.

The full nationwide scope of the NDIS will not be a reality until the Commonwealth Government allocates specific funding in its budget, which it has not yet done at the time of writing.

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[13] NSW Ageing, Disability and Home Care (2011) *Stronger Together: The Second Phase 2011-2016*, Sydney.

[14] ADHC (2012) *Putting people with disability at the centre of decision making: Outcomes of statewide consultations May – August 2012*, Sydney, available at: http://www.adhc.nsw.gov.au/about_us/strategies/person_centred_approach/person_centred_approaches_consultations (last accessed: 25/02/2013), see chapters 2-3, and Appendix 1.

[15] See Commonwealth of Australia (2012) *National Disability Insurance Scheme*, Canberra, at: http://www.ndis.gov.au/ (last accessed: 08/11/2012).

A number of people using community care services will be eligible for support under an NDIS. It is not yet clear whether people with disability eligible for community care support will be able to access support through the NDIS, despite funding for community care in NSW being transferred to the NDIS.

Living Longer, Living Better aged care reforms

Aged care reforms have been taking place at the same time as disability reform. HACC service providers know that, for non-Aboriginal people over 65 and Aboriginal and Torres Strait Islander people over 50, HACC services will be incorporated into the Commonwealth Home Support Program. There are parallel changes in other parts of the aged care sector which are similar, but not identical, to person centred approaches in the disability sector. These reforms will also affect the community care sector, and so community care providers may be more familiar with them. However, implementing these new approaches in aged care should not be confused with fully realising a person centred approach.

Consumer Directed Care

At the Commonwealth Government level, the *Living Longer, Living Better* reforms have initiated transformations in community aged care. Aged care packages – now known as CACP (Community Aged Care Packages), EACH (Extended Aged Care at Home) and EACH-D (Extended Aged Care at Home – Dementia) – will be offered on the basis of Consumer Directed Care (CDC).

CDC involves a consumer of services having greater autonomy and choice in decision-making about how services are delivered, when, and by whom. A personal budget is allocated to a service provider for each package recipient, who works with the provider to direct how it is spent.

However, there are many elements of CDC implementation in aged care in Australia that differs from person centred approaches in disability support. Person centred approaches begin from a human rights perspective, while CDC is focused on consumer rights. CDC packages are allocated to a service provider, not directly to a person. Packages will conform to a series of 4 pre-defined 'levels', rather than responding directly to the needs of the person. CDC will involve a list of specified service types from which a person can choose, and they must make a case for choosing outside of that list.[16] NCOSS is concerned that some peoples' choices may be restricted under this approach, particularly Aboriginal people using a package held by a mainstream service provider e.g. an Aboriginal person may not be able to use their package to support them to return to country.

[16] Department of Health and Ageing (2012) *Consumer Directed Care and Home Care Packages Program Overview*, 16 November 2012, Canberra, available at: http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/Consumer-Directed-Care-Home-Care-Packages-program-overview (last accessed: 26/11/2012).
The advisory body appointed by the Department to provide recommendations about CDC proposed that CDC operate on an exclusion approach, with very limited services ineligible for funding from a CDC based home care package. See National Aged Care Alliance (2012) *National Aged Care Alliance advice on phase one development of Consumer Directed Care (CDC) Home Care Packages*, Canberra, available at: http://www.naca.asn.au/naca-login/Home_care_CDC.pdf (last accessed 12/11/12), for details about how CDC may operate in aged care.

Home Support Program

Under *Living Longer, Living Better*, the Commonwealth HACC Aged Care Program will be merged with the Assistance with Care and Housing for the Aged Program, Day Therapy Centres, and the National Respite for Carers Program into the Home Support Program. Details of the Home Support Program are not yet available, including any plans to provide Home Support Program services on the basis of CDC.

Enablement

Enablement, or the Enabling Approach, aims to focus service provision on supporting a person to be independent, and to reduce inappropriate use of services. The Enabling Approach involves a transformation of service provision such that it is more responsive to individual strengths, aspirations and preferences, and more actively involves a person in decisions about how support is provided to them.

Approaches similar to Enablement have been in use across Australia in HACC services for a considerable amount of time.[17] The IMPACT Working Group in NSW advocated and promoted the approach[18], and it is being promoted across community care services in NSW through the ADHC Better Practice Project.[19] However, the Better Practice Project has thus far focused on older people and not younger people with disability.

The *Living Longer, Living Better* reforms also focus on 'reablement', which has a greater emphasis on limiting service dependence than on older people exercising choice and control in how they use support. Implementation of an Enabling Approach alone will not result in person centred support for people with disability.

Person centred approaches in disability support

NCOSS supports the implementation of person centred approaches across disability support in NSW.

Person centred approaches do not involve a single method or mechanism, but have in common a focus on the autonomy of the person with disability. That is, person centred approaches focus on a person with disability exercising **choice** and **control** in how supports are managed, arranged and delivered in their lives. Person centred approaches begin from a human rights basis, particularly relying on the *Convention on the Rights of Persons with Disabilities*.

Models of disability support differ in how much choice and control is afforded to the person with disability and their carers/families; some offer more choice and control than others. There is a continuum of how person centred a particular model or mechanism can be.

[17] In each State and Territory where the approach is used, there are different labels it is known by: wellness (SA & nationwide), Active Service Models (Vic), Restorative (WA), Strengths-Based Approach (NSW Community Options). The approach is also known as re-ablement in the UK (this is also the term used by the Productivity Commission in its 2011 *Caring for Older Australians* Inquiry Report).
[18] See the IMPACT NSW website at http://impactnsw.com/ (last accessed: 12/11/2012).
[19] NSW Ageing, Disability and Home Care (2010) *A handbook for community care services: Empowering people, enhancing independence, enriching lives*, Sydney, available at: http://www.adhc.nsw.gov.au/__data/assets/file/0003/233967/Better_Practice_Project_-_Mapping.pdf (last accessed: 10/10/2012).

Person centred approaches also move away from traditional service provision that is constrained by guidelines, service type boundaries, data categories, and output requirements. What is most important in person centred approaches is supporting a person with disability to live the life they want to lead.

Person centred approaches employ a variety of mechanisms including:

Self-directed support or individualised funding

Self-directed support/individualised funding involves a budget allocated to a person on the basis of assessed needs and an approved plan. The budget can be held and managed directly by the person, managed by a fund holder, or allocated directly by the person to a service provider. People with disability and their carers and families must also be able to access other infrastructure to use self-directed support/individualised funding successfully:

- **Expert advice**, including decision support resources, to assist in developing the tailored package of supports, with planning and options for using a personal budget; and/or
- **Financial intermediary** who, if required, manages the mandatory requirements and accountabilities for the funding, e.g. finances, legal obligations, industrial issues, contracting, and workplace health & safety.

Under this mechanism, a person can employ a worker directly and choose the hours which they work, purchase services from a variety of providers, use mainstream and non-traditional disability supports (e.g. some assistive technologies, support activities that have the effect of respite for a carer), and take their budget with them when they move location.

Individualised/self-directed funding will be implemented in NSW from 1 July 2014, when people using specialist disability services can convert the value of those services into a portable, individual funding arrangement. The NDIS will also involve self-directed/individualised funding.

Person centred planning

Person centred planning involves planning that commences from considering a person's strengths, skills, wishes, aspirations and preferences. Instead of an assessor making a decision about a person's deficits, and planning services to compensate for those perceived deficits, person centred planning is driven by a person's choices. ADHC's *Lifestyle Planning Policy* and *Guidelines*[20] outline principles and practice that can achieve person centred planning.

Self-managed model/package

People using some disability day programs in NSW have had the option to convert the value of their day program service into an individualised package. While the funds are held by service providers, and not directly by the person, the person with disability, with their carer and family, is able to make choices about using the funds that would not be available under a day program. However, self-managed packages usually offer fewer hours than a group day program.

[20] ADHC (2011) *Lifestyle Planning Policy*, Sydney, amended August 2012, available at: http://www.adhc.nsw.gov.au/__data/assets/file/0005/241088/Lifestyle_Planning_Policy_Aug_2012.pdf (last accessed: 26/11/2012).

Networks/circles of support

A network/circle of support involves group of people who choose to come together formally to join on decision making and support with/for a person with disability. These can be formally incorporated, or be an informal commitment by the members.

Many of these mechanisms have been operating in other countries, the UK in particular, and other states, for many years.

Conclusion

Person centred approaches are an important component to people with disability realising human rights and enjoying a quality of life. Extending access to a person centred approach to people currently using community care services is essential to ensuring that people with disability in NSW are able to enjoy enhanced life opportunities.

Person centred approaches are possible in community care in NSW through a well-considered implementation process involving all stakeholders. By working together, we can create better options for people with disability.

For further information, contact:

Rashmi Kumar
NCOSS Senior Policy Officer – *older people, carers & community care*
66 Albion Street, Surry Hills, NSW 2010
Ph: (02) 9211 2599 ext. 108
Fax: (02) 9281 1968
Email: Rashmi@ncoss.org.au

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Further resources

The following resources provide practical advice and accounts of how person centred approaches have been successfully implemented in other areas.

Holburn, S. and Vietze, P. M. (eds) (2002) *Person-Centered Planning: Research, Practice and Future Directions*, Paul H Brooks Publishing Co., Sydney.

Mercer, M. (2003) *Person-Centered Planning: Helping People with Disabilities Achieve Personal Outcomes*, High Tide Press, Homewood Illinois.

Centre for Welfare Reform & Self Direct (2010) *Helping Providers to Change*, Sheffield, available at: http://www.selfdirect.org/documents/64/Helping-providers-to-change.pdf (last accessed: 28/11/2012).