



Council of Social Service of New South Wales

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Ms Patricia Scott
Commissioner
The Productivity Commission
Email: disability-support@pc.gov.au

Re: Response to the Disability Care and Support Inquiry Draft Report

Dear Ms Scott

Please find following the Council of Social Service of NSW (NCOSS) submission to the Draft Report on the Disability Care and Support Inquiry.

NCOSS Senior Policy Officer Christine Regan met and congratulated you at the Disability and Carers Alliance Congress in Melbourne last week, and advised that our submission was still under development and would be forwarded shortly. This was also indicated in a previous email to the Commission dated 27 April 2011. Thank you for confirming the website advice that submissions would continue to be received past the April due date.

NCOSS appreciates the opportunity to provide feedback to the proposals contained in the draft report and congratulates the Productivity Commission on an important and significant advancement of the needs, rights and interests of people with disability and their families and carers across Australia.

NCOSS looks forward to the prompt public release of the final report to inform the sector and to honour the participation of the respondents.

Yours faithfully

Alison Peters
Director
NCOSS

About NCOSS

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

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

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, 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, church groups, peak organisations and a range of population-specific consumer advocacy agencies.

OVERALL COMMENTS

- NCOSS strongly agrees that the current system of disability support service is underfunded, unfair, fragmented and inefficient. Consequently, adequate new funding must be provided to disability supports to ensure that people with disability across Australia have access to the range of life opportunities and choices generally taken for granted by non-disabled people of the same ages. Not to do this is a colossal waste of valuable human potential and a no-win cost to the public purse.
- NCOSS strongly agrees that there should be a National Disability Insurance Scheme (NDIS).
- A proposed NDIS must provide long term high quality care and support to people with disability.
- NCOSS very strongly supports the provision of individualised support packages and that these must be universally available. Individualised packages must be driven by the decisions of the person with disability.
- NCOSS also agrees that the NDIS must be operated on an entitlement basis.
- NCOSS strongly supports the portability of support packages and assessments of need, across all borders.
- An individualised package will create opportunities for the person with disability to decide to use the disability specialist system and/or any other supports that meet their personal needs and goals.

- NCOSS agrees with the Productivity Commission proposal that there be two schemes in the initial phase, an NDIS and the National Injury Insurance Scheme, as long as there is a guarantee that after 5 years this is reviewed to assess the feasibility of amalgamation into one overall scheme.
- NCOSS also agrees that the NDIS should complement, not replace, the obligations and responsibilities of mainstream Government and other agencies to engage with, involve and provide services to people with disability. In other words, the Health, Education, Housing, Employment and Transport sectors, for example, must continue to lift their game in responding to people with disability separate to the NDIS. Further, an essential and necessary role of the National Disability Insurance Agency (NDIA) will be to provide leadership for mainstream sectors and a mechanism for ongoing accountability of these sectors in disability social inclusion and economic participation.
- NCOSS agrees with the proposed timeframe of commencement from 2014, with extension Australia-wide in 2015 and progressive expansion to cover all people with disability.
- NCOSS further supports a *savings clause* that nobody should be worse off under an NDIS.
- NCOSS agrees that the NDIS should be legislated, with funding managed into a separate account, by a body separate from existing government bureaucracies, the National Disability Insurance Agency.

FUNDING SOURCES

NCOSS is concerned the Productivity Commission is recommending that the funding for the NDIS is raised from consolidated revenue, using a legislated formula and possibly diverting funding from “lower priority” areas. NCOSS would oppose any funding stream that became a competition among human services spending or that reduced funding to one group of disadvantaged people and communities towards other disadvantaged people and communities.

A UNIVERSAL SYSTEM

NCOSS believes that NDIS individualised packages must be universally available.

A person receiving an individualised package could choose, at one extreme, to do nothing and maintain a primary support relationship with their disability organisation. Then, over time, as the person sees that others are making more creative choices with their packages, the person might have more confidence to vary their package to be more responsive to their contemporary needs.

At the other extreme, a person might choose to cash out their package and manage it without external intervention, besides accountability. It is expected that most people with disability will engage both professional advice (in the design and implementation of their plan) and a financial intermediary (to fulfill financial, accountability and contractual obligations) to manage their package.

A RIGHTS BASED APPROACH

The NDIS must genuinely and openly adhere to/comply with the United Nations Convention on the Rights of People with Disability (UNCRPD). Further, all federal, state and territory legislation must be reviewed to ensure the facilitation of the NDIS in all jurisdictions. Building on this, the NDIS must entrench the National Disability Quality Standards.

AN INCLUSIVE SCHEME

NCOSS contends that people with disabling conditions arising from a mental illness or other mental health issues must be included in the NDIS. Treatment, as for all other people, must be provided by the Health system but people with ongoing significant non-treatment support needs must be able to access to NDIS.

Similarly, people with disability at or past age pension eligibility must be included in the NDIS. NCROSS cautions that this applies to older people who have a disability *not* arising from the ageing process. People whose support needs arise from the ageing process must remain the responsibility of the Aged Care system.

NCOSS fully supports the submission of the NSW Aboriginal Community Care Gathering Committee in ensuring that the NDIS is available, accessible and useable by Aboriginal and Torres Strait Islander people with disability and their families. NCROSS notes that in many Aboriginal families and communities, the disability of a child or adult may not be specifically identified, thereby preventing access to necessary financial, practical, developmental and social supports to assist that person in life chances and opportunities. NCROSS further insists that

- the development and commencement of the NDIS contains both general access and specific outreach strategies to engage with Aboriginal people and communities as an initial implementation activity i.e. at the front end.
- the take-up and usage of the NDIS by Aboriginal people is a Key Performance Indicator for progress reports and review and evaluation process of the Scheme.

People from culturally and linguistically diverse communities must similarly be included at the outset with specific strategies to for them to be engaged, access and use the NDIS during development and from commencement.

THE PERSON WITH DISABILITY DECIDES

Individualised packages must be driven by the decisions of the person with disability. NCROSS contends that all people can participate and direct the decisions that affect their lives. Those closest to people with the very highest support needs can describe what makes that person happy or sad, what gives them joy, what frustrates them, what they prefer or detest, what makes them angry and what delights them. Using this information, even people with extremely high support needs can direct the decisions that shape their lives.

Accordingly, NCROSS advises the Productivity Commission to refer, always in the first instance, to the person with disability as the expert in their own life, regardless of whether that person has a legal guardian or family/carer. Then, running a very close second, the carer, family and/or guardian can be consulted to determine appropriate decisions and choices.

CARERS AND FAMILY

NCOSS uses the definition of *carer* as described by Carers NSW:

Carers are usually family members who provide support to children or adults who have a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who are frail. Carers can be parents, partners, brothers, sisters, friends or children of any age. Carers may care for a few hours a week or all day, every day. Some carers are eligible for government benefits, while others are employed or have a private income¹.

NCOSS does not subscribe to the term *informal* carer because the care and support provided by the carer is very often of a significant and essential nature; therefore not *informal* which implies care of a relaxed, casual or easy nature. People who are paid (or indeed volunteer through a disability support agency) are workers or staff, not carers.

NCOSS advises that the needs of the person's carer, family, guardian must be acknowledged and addressed within the assessment process, as well as their willingness and expressed capacity/capability to continue in their caring role. Carer capacity must not be a limiting factor for an individual package to a person with disability. One's rights must not supersede the rights of the other, nor their access or entitlements.

CO-PAYMENTS

Many people with disability with significant support needs already rely on income support or on low fixed incomes for their daily living requirements. A co-payment obligation could prove divisive and inequitable for these people. NCOSS believes that, similar to other required "donation" or co-payment schemes, it may cost more to regulate and administer this scheme than the amount of money it actually collects.

THE IMPORTANCE OF ADVOCACY AND INFORMATION

The use of advocacy and information services will be a critical factor in the acceptance, access to, implementation and success of the NDIS to people with disability in Australia. Advocacy and information at local, regional, state and national levels, individual and systemic advocacy, must be freely available in many formats and at critical points in a person's life or when circumstances change, is an essential connector and bridge between the bureaucratic and government and provider systems for people with disability. Effective independent advocacy and information can raise the confidence of disempowered people, can initiate and prove the worth of systemic change and can ensure continuous engagement and improvement of the social inclusion of people with disability and their families.

NCOSS strongly argues that access to and use of advocacy and information support and services must not be part of a person's individualised package.

Under the Productivity Commission proposals, advocacy and information could support all three Tiers of possible users of the NDIS:

- Tier 1: Advocacy and information would offer awareness and assurance for everyone as well as leadership for the non-disabled community to engage with and involve people with disability
- Tier 2: Advocacy and information would support people affected by disability requiring active and explained information and referral, ensuring essential linkages

¹ From the Carers NSW website <http://www.carersnsw.asn.au/Default.html?/aboutcarers/whoare.htm>

- Tier 3: Advocacy and information is crucial to people on individualised packages, where decision are difficult, where external agencies may be approached, where there is disagreement, where people require an independent person to assist them to be heard

Advocacy and Information Is Not Part of an Individualised Package

At present in NSW, advocacy and information is over and above the support a person with disability receives. This is because advocacy support is separately funded and reported from direct service provision by disability service organisations. NCOSS contends that the provision of information and advocacy must be separate to a person's individualised package and separately funded.

Carers' Access to Advocacy

When a carer is the primary decision-maker alongside the person with disability, there are times when an approach to advocacy and information organisations could be made by the carer in order to maintain the desired supportive caring relationship. If the person's individual package was tightly regulated towards outcomes specifically for that person, as it must be, it could be decided that the carer's need for advocacy might be *surplus to requirements* for the package. This could create a perverse result directly affecting the person with disability whom the package was designed to protect.

For some people with disability, their carer and family will be the major assisting decision-makers. The vast majority of carers and family members act in the best interests of the person. However, when there is a conflict of priorities or in fact when the person and carer disagree, advocacy must be available to the person with disability to assert their wants/viewpoint, separate from their individual package. Where the control of the individual package is shared with the carer, a carer in conflict could deny expenditure on advocacy to the person with disability requiring it, if the individual package was the only way advocacy could be obtained. Therefore advocacy and information must not be part of the individual's package.

Third Party Involvement

Sometimes, people with disability have few relationships outside the immediate family or the home. This is not a regular or healthy situation for any person, especially a person with disability. NCOSS is aware of many approaches to advocacy organisations from external people, (e.g. neighbours, shopkeepers) who have concerns for the person with disability but do not feel able or appropriate to approach the person or family directly. Advocacy and Information must stand alone so that the interests of the person with disability can be protected and promoted.

On Entry

Many people need advocacy to enter the system and may not already be in receipt of formal services. The Productivity Commission has acknowledged that the very people with disability who will access NDIS individualised packages are people who are extremely unlikely to have accumulated financial resources, or indeed wealth, to be able to afford fee-for-service advocacy services. Therefore, people without individualised packages will be denied the essential support of individual or systemic advocacy to even enter the system. Therefore advocacy and information services must be separately funded and not part of an individualised package.

People with Individualised Packages

People who have a carefully designed plan for the expenditure of their packages must not be forced to choose between direct support and necessary advocacy. In other words, if a

package is fully expended and a need for advocacy arises, it is unacceptable to expect that a person forgoes necessary support in order to use advocacy services.

People without Carers or Significant Others

Many people with disability have little or no access to carers, family or significant others. The role of advocacy and information may not be continuous for many of these people but will be absolutely necessary at life transitions, changes of circumstances, illness etc. The use of advocacy must not be contingent on the adequacy of a person's package.

Advocacy Beyond Disability Service Providers

Independent disability advocacy and information services inform NCOS that people with disability may require advocacy in all aspects of their lives, not just in their need for support. Issues of access and use of health services, housing, transport, the built environment, employment, local government etc form part of the regular workloads of disability advocacy services. Sometimes advocacy is simply to access or to find the right person or agency in the system, sometimes it is to seek a resolution. At significant life transitions, e.g. death of a parent, the advocacy could be intense and take longer. Such advocacy must not be limited to interactions with the disability services system or must not rely on the person's package to assist with wider aspects of a person's life.

Independence

The Productivity Commission has heard of the conflict of interest when direct service providers assume individual advocacy responsibilities on behalf of their clients. A trust relationship is critical to quality support from providers. However, if the worker assisting with internal or external advocacy works for your direct service provider, the opportunities for conflict of interest are rife. NCOS believes that the provision of advocacy and information must be separate from direct service provision. This also avoids the "captured market" syndrome where, in advocacy, clients are only offered alternatives/opportunities within the service organisation rather than the most responsive, possibly external, option.

Systemic Advocacy

In economic terms, it is not good business to solve the same problem multiple times. It is much better to create a system-wide resolution that avoids future complaints. While advocacy at the individual level must inform systemic advocacy, systemic changes cannot be achieved by individual packages.

Legal Aid Analogy

A useful analogy is the legal aid system. In order to create fairer access to legal support, intervention and recourse, a system of government-subsidised legal aid agencies is available across Australia. This is designed specifically to provide legal access to people not financially able to afford the regular system. As explained, people with disability without personal resources may not be able to access advocacy when needed simply because their individual packages are completely committed to purchasing necessary supports. Similarly, a system of independent advocacy and information services must be separately funded, not using individualised packages.

CONNECTIONS WITH HACC

NCOS notes that many of the supports listed in Box 2 of the Overview are the same service types as currently provided under the soon-to-be-disbanded Home & Community Care (HACC) Program. In NSW, more than 50,000 people with disability (people aged under 65 years) use HACC services to remain in their own homes. This equates to approaching 200,000 people with disability Australia wide using HACC. At present under the COAG decision of April 2009, HACC as a program will formally cease to exist from 1 July 2011 with the new jurisdictional arrangements formally commencing on 1 July 2012. This means that all HACC organisations servicing people with disability will become part of the disability system

and all HACC providers to older people will become part of the aged care system. The COAG communiqué states there will be no change to the eligibility or provision of HACC services before June 2015.

At present in NSW, aside from HACC, there is very little or no option for essential in-home support services to people with disability and their families under the existing disability service system. There are concerns that people with disability now using relatively low level HACC services to maintain them at home may not be eligible under the NDIS. If they are not, how can they continue to receive the necessary supports to remain living in the community?

NCOSS is concerned that, with the dispersal of HACC, valuable in-home support, expertise and experience could be lost without careful attention to maintaining the strengths of HACC into the future. Given the number of people with disability affected by these changes, this will be a significant consideration in crafting the NDIS and its implementation. Former HACC funding to support people with disability could supply an additional guaranteed income stream in the medium term that could complement the NDIS, similar to the proposed NIIS.

NCOSS advises that the NDIS should carefully gather and safeguard the resources, expertise & experience, available volunteer and paid workforce, and the genuine in-home philosophy of the HACC program for people with disability.

AGED CARE AND ABORIGINAL PEOPLE

Aboriginal people can access HACC services at age 45+ years, due to the age gap in life expectancy. Under proposed transformational changes to the aged care system, Aboriginal people will only be able to access proposed aged care services at 50 years. From then, Aboriginal people can decide to use either the disability or aged care systems but the Commonwealth will pay for those services. For many people this 5 year eligibility gap will be a critical time, possibly severely disadvantaging people who, by reason of frailty rather than identified disability, may be in need of critical support services. This is a significant point of confusion between proposals of the Productivity Commission's disability and aged care inquiries.

A further inequity is that, under proposed changes, people reaching 65 years, or 50 years for an Aboriginal or Torres Strait Islander person, will be subject to the means test on entering the aged care system. NCOSS acknowledges that a very small proportion of Aboriginal people are likely to be affected, but an inherent inequity is that mainstream people will be means assessed after at least 65 years of opportunity to accumulate assets/resources/wealth but Aboriginal people will have only 50 years before the same assessment is applied. Into the future, this could be increasingly inequitable.

NCOSS fully supports the NSW Aboriginal Community Care Gathering Committee submission to the Productivity Commission National Disability Care and Support Inquiry Draft Report.

NATIONAL DISABILITY INSURANCE AGENCY

The National Disability Insurance Agency (NDIA) is proposed to be the governance body for the NDIS and there will be an advisory committee of disability experts. NCOSS understands that the Governance composition of the NDIA is almost solely people with finance expertise. NCOSS strongly recommends that the NDIA Board of Governance directly includes a number of people with disability at the top level. In this way, the financial and operational aspects of the NDIS can include real expertise on the actual subject matter as well as insurance/financial expertise. NCOSS believes this expertise must co-exist on the Board.

Alongside the Governance Board, the proposed Advisory Committee will play an integral role in continuing to refine and improve the NDIS as it operates. But this will only be possible if the Advisory Committee has delegated powers to act and to make enforceable decisions. The NDIA should not be able to ignore advice from the Advisory Body, nor should this important Committee be constrained to provide advice solely to the Board. Consequently, the Advisory Committee must comprise people with disability across the range of disability conditions and impacts, life circumstances, diverse cultures, economic backgrounds and localities; people with significant expertise and experience in high level advice.

NCOSS believes there exists an extensive pool of people with disability who have the required skills and abilities for appointment to both the Governance Board and the Advisory Committee.

In order to create confidence in the new NDIS system, there must be transparency of public reporting on a regular basis. Scheduled public reports to Parliament would be advisable.

Conclusion

NCOSS appreciates the opportunity to provide feedback to the proposals contained in the draft report and congratulates the Productivity Commission on an important and significant advancement of the needs, rights and interests of desperate people with disability and their families and carers across Australia.

NCOSS looks forward to the prompt public release of the final report to inform the sector and to honour the participation of the respondents.