



## Council of Social Service of New South Wales

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2 July 2009

The Respite Directorate  
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Dear Respite Directorate

<p><b>RE: NCOSS Submission to <i>New Directions for Disability Respite Services Discussion Paper</i></b></p>
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NCOSS appreciates the opportunity to provide feedback on the *New Directions for Disability Respite Services Discussion Paper* and is grateful for the slight extension to the deadline. This submission is structured in two sections, overall comments and specific comments in relation to sections of the Discussion paper.

The Council of Social Service of New South Wales (NCOSS) is the peak body for the social and community services sector in New South Wales. NCOSS works with its members on behalf of disadvantaged people and communities towards achieving social justice in this State.

NCOSS provides an independent voice on human services policy issues and social and economic reforms and is the major co-ordinator for non-government social and community services. It was established in 1935 and is part of a national network of Councils of Social Service, which operate in each State and Territory and at Commonwealth level.

NCOSS is willing to engage in further discussion regarding improvements to the respite system. We look forward to your written responses to the questions/queries contained in the submission.

Should any clarification or further information on the feedback be required, please contact Christine Regan on 9211 2599 ext 117 or [chris@ncoss.org.au](mailto:chris@ncoss.org.au).

Yours faithfully

Alison Peters  
Director

# Overall comments

NCOSS considers respite to be provided to both the carer and the person with disability. The new Framework is an opportunity to redefine respite in this way, especially as the actual respite services are provided to the person with disability while the carer benefits from the respite effect. This also recognises that, while the carer may need time out from their caring role, the person with disability may equally need time out from the carer.

NCOSS recommends that DADHC aligns the new respite framework with all other respite and related programs providing respite to people with disability and carers, including HACC respite, especially in-home and peer support, older parent carer programs through Commonwealth Department of Health and Ageing and other programs from other Commonwealth and state government departments.

Respite is often used by both consumers and assessors/service providers as a band-aid solution in the absence of more appropriate supports specifically for the person with disability. NCOSS acknowledges that if the service system adequately addressed the needs of children and adults with various disabilities, the existing burgeoning unmet need for respite could diminish to a point where respite truly provided time out for the person and their carer.

DADHC must be careful in describing respite that the needs of the person with disability are always equally considered. While acknowledging that respite is an evolving service, DADHC must be cautious not to frame respite in terms of

- maintaining the family situation where the person or the carer does not want this
- mainly avoiding relinquishing care when this is the best solution for the person and carer
- a cheaper solution, ie not providing more suitable but possibly more costly service supports
- a stop gap measure to avoid or delay abandonment or neglect

The provision of respite should not be solely disability specific, as in the specialist disability service system being the only answer. The provision of respite should be disability responsive, and include the use of mainstream or non-disability-specific activities or pursuits according to the person's interests or preferences.

# Specific comments

## Principles

NCOSS supports the Principles identified in the Discussion Paper.

NCOSS supports references in the Principles to *person-centred*, *flexible* and *individual needs* but is aware that these do not either fully support or clearly describe new approaches to **self-directed supports**. Each of the referenced terms may indicate quality services, implying an individualised approach but the terms can equally apply to services receiving block grants for fairly generic supports to groups of consumers (each of whom writes an Individual Plan as part of their participation in the service). Self-directed packages refers to a support approach where the person and their family makes the decisions and is in control of how and on what the funding is spent, regardless of their involvement in the actual management of the money and contracting etc. NCOSS would like to see a suite of self-directed packages implemented, ranging from situations where the person and family has all decisions but none of the paperwork to situations where the person and family is responsible for the entire package, its spending, contracting and accountability etc. This suite of packages will also include a mix of choices between these extremes. NCOSS has been in discussions with Judy Harwood at DADHC regarding how self-directed packages can be structured and is aware of the Expert Advisory Group advising DADHC on this very issue. Consequently, the possibility of self-directed packages could be made clearer in the Principles.

- **services are cost effective.**

NCOSS knows that respite is certainly cost-effective, research and experience clearly indicating that timely appropriate respite delivers significant cost benefits over time. NCOSS is concerned, however, that this Principle could present an unreasonable barrier to providers if it becomes a condition of funding for respite. Many of the outcomes and benefits of respite emerge in the medium to longer term so a requirement to demonstrate short term cost effectiveness could be an unintentional burden. Efficient service provision should be demonstrated and should be part of a continuous improvement strategy for providers.

## Other services that give carers a break

NCOSS takes issue with this heading over a list of community based services offering carers “a break”. Child care is listed as allowing carers to participate in education or employment. For parents of children without disability, education or employment is not considered a *break* from their children, so neither should DADHC apply this to families of children with disability. School is not provided to give families a break from children and young people but to educate and develop them. Similarly, post school and day programs are provided to young people and adults with disability. DADHC must be wary of labelling any time apart as respite for the carer because respite has a specific purpose. People with disability and their families must have the same life opportunities as other people and families at similar life stages for the same reasons, but will require additional supports to access them.

## **Client feedback tells us**

NCOSS suggests additions to the client feedback section. DADHC needs to interpret the client feedback into service responses. The service system, not just individual services or providers, should meet the changing needs of people with disability. DADHC should acknowledge that people with a range of disabilities and their families require respite and a range of supports, obviously including physical and other disabilities.

## **Research tells us**

NCOSS speculates that factors contributing to the growing demand for respite services could also include

- changes in generational expectations
- the fact that mothers begin their families at older ages than in previous generations

## **Priority groups of carers**

### ***Working carers***

NCOSS absolutely acknowledges the needs of working carers of school aged children. DADHC correctly recognises that working parents of teenagers with disability will require after school care to remain in employment or education and has identified this group as a priority. Similarly, this seems to overlook the needs of working carers of people with disability attending post school and day programs. Typically, post school and day programs operate for similar hours as school on a daily basis. Therefore, working parents would similarly require respite for the extra time while working. Many post school providers cannot provide additional time for respite to support working carers. Adult programs do not have school holidays so the need for vacation care for adults is different from the needs of school aged children.

### ***Hidden carers***

The Discussion Paper rightly identifies the needs of hidden carers. The Paper does not acknowledge the needs of the people with disability supported by hidden carers. It is highly likely that the isolation of the hidden carer has equally isolated the person they care for. In this case, the needs of the person with disability must be a primary consideration alongside that of their carer.

### ***Aboriginal and Culturally and Linguistically Diverse (CALD) carers***

The strong focus on building organisational capacity to respond to a diverse range of clients is only part of the answer. It is clear that Aboriginal and CALD families prefer home based and packaged services, as evidenced by their proportionally strong use of community care packages and HACC (refer Productivity Commission usage rates). Accordingly, individualised packages and self-directed supports could be preferred and viable support options for these groups.

## The way forward

NCOSS fully supports the four key themes on page 9.

## Expanding services and developing new service models

### *Families Solutions Program*

While the risk of relinquishing care is paramount for this program, an important eligibility criterion for access to service should also be the improvement of the family's capacity to cope.

### *Teen Time*

Refer to earlier comments for the respite needs of young people and adults in post school and day programs.

### *Leisure Link*

Again, the necessary priority of people with challenging behaviours is acknowledged and appropriate. It should not be forgotten, however, that people with high support needs and their families must also be able to access recreational respite. The compatibility of service users is crucial to successful individual and program outcomes and DADHC should reprioritize this as a service requirement.

### *Respite Camps – specialised camps*

The inclusion of siblings is an innovation in respite camps for teens with moderate to high support needs. It should not, however, be a condition of attendance at all specialised camps. Siblings programs can also be provided separately. Many siblings are also in need of time apart. Refer to the attachment: **Coming Down the Mountain**: the review of a UK telemovie which portrays the near tragic impact of his brother's disability on a young man.

## Older Parent Carers

While NCOSS fully supports the provision of respite services to people with disability and their older parent carers, respite should not be a lower cost substitute when supported accommodation would be the more appropriate service response. Supported accommodation priority should be given to people with disability whose carers are aged in their seventies and eighties, as a matter of urgency.

## **People with challenging behaviours**

The focus of DADHC programs is clearly weighted towards children and young people with challenging behaviours. There is significant unmet need for respite and other services for adults with challenging behaviours.

## **High support and complex health care needs**

NCOSS supports the strategy of providing supplementary nursing staff to respite services on a purposely planned basis. This strategy could change the nature of some existing respite services and does not address the need to increase respite capacity. DADHC would be well advised to reprioritise compatibility in respite service users to protect and improve individual and program outcomes.

## **Degenerative neuromuscular illnesses and acquired brain injury**

Again, individualised packages and self-directed supports could be preferred and viable support options for these groups.

## **Giving individuals greater choice**

### ***Individualised (packaged) Support***

NCOSS strongly recommends accelerating this form of support to increase capacity and improve outcomes for people with disability and their carers. Refer to comments under the Principles section of this submission for further explanation.

### ***Flexible respite places***

The identified areas of unmet need in the Discussion Paper seem to indicate the development of “innovative” disability specialist services only. NCOSS recommends that the identified areas of unmet need could also be equally well served by facilitating supported access to mainstream activities. This could work for people with a diverse range of disabilities and interests and abilities. This approach could apply to children, young people and adults with disability while providing necessary respite for the carer.

## **Streamlining access to services**

### ***Intake, assessment and eligibility***

NCOSS considers the provision and use of respite services to be a complex undertaking. The *Stronger Together* commitment to improved service systems is critically important but the development of a simple system to address disparate and very complex issues might be unreasonably ambitious. Access to this complex service system, however, need be neither unfathomable nor highly complicated so the development of a simplified coordinated access system for respite services could in itself improve program efficiencies.

### ***Regional initiatives***

In the development of improved access to respite services, DADHC should avoid the creation of bottlenecks. Further, in any vacancy matching system, particular care is necessary to avoid referring desperate clients into available but inappropriate respite options.

### ***Sector Development Strategies***

The Discussion Paper briefly describes several initiatives including the *Strategic Funding Reform Project* and *Improving Service System Accountability*. NCOSS is interested in more information about these initiatives and is eager to discuss these initiatives with DADHC. Please advise where NCOSS can obtain further information.

## **Conclusion**

The goal of a flexible responsive disability respite system is well described in the Discussion Paper and fully supported by NCOSS. Further, improvements to the service system should contribute to increased capacity. DADHC must not depend on constant service review and service efficiencies to address the burgeoning unmet need for respite services. Planned and accelerated investment is required, in addition to the second phase of *Stronger Together*, including increased funding towards individualised and self-directed supports.

## **NCOSS conclusion**

Please refer to the following attachment to illuminate the needs for respite of the siblings of people with disability, as discussed under Respite Camps. This article was published in the June 2009 edition of INTERACTION.

NCOSS appreciates the opportunity to provide feedback on the New Directions in Respite Discussion Paper and is grateful for the slight extension to the deadline. NCOSS is willing to engage in further discussion regarding improvements to the respite system. Should any clarification or further information on the feedback be required, please contact Christine Regan on 9211 2599 ext 117 or [chris@ncoss.org.au](mailto:chris@ncoss.org.au).

## A review of **COMING DOWN THE MOUNTAIN**

By Christine Regan

Published in INTERACTION June 2009 edition

The National Professional Journal on Intellectual Disability

“Last summer I decided to kill my brother.” These are the opening words of a BBC drama, recently shown on ABC TV1. Produced in 2007, this 90 minute television production was written by Mark Haddon, author of *The Curious Incident of the Dog in the Night-time*, directed by Julie Anne Robinson, and starred Nicholas Hoult and Tommy Jessop.

The story is about David, a young man in his mid teens whose teenaged brother Ben has Down syndrome. Living in London, the family also comprises Mum and Dad who rely on David to shepherd Ben to and from school etc while both work.

David observes that he has never been more than 6 feet away from Ben his entire life and his growing resentment manifests in increasingly precarious and erratic behaviours. When David’s best friend invites him to an after school party, David for the first time sends Ben home alone on the bus.

At the party David meets a long admired Gail and during their first kiss, the party comes to an abrupt halt as David’s Mum and Ben arrive to collect a humiliated David. A neighbour found Ben who had missed his stop. On the way home, David remembers that he has in fact been away from Ben and his parents for a week at a school camp remembering the “happiest week of my life.”

The teenage angst is very real and increasingly dangerous. Ben is present in David’s life only as a responsibility, not really a person or a brother. Similarly, while clearly in a loving family, Ben is treated more as a child than as the young adult he is becoming.

The situation spirals towards crisis when the family moves a hundred miles out of London to Devon so that Ben can go to a better school. After the move, David finds he is losing his friends and his newly regained girlfriend.

In a spontaneous life-altering decision, without telling their parents, David packs up Ben and they go camping in North Wales. This is the trip where David plans to kill Ben. They climb a steep mountain and after a sharp exchange with his brother, an enraged David shoves Ben off the cliff.

After a dramatic helicopter rescue, David finds Ben in hospital, sitting up and only battered and bruised. When Ben threatens to report him for attempted murder, David drags his brother away before any details can be taken down. The story unfolds as David and Ben eventually find themselves together again by the camp fire. A real conversation. David is beginning to discover hidden depths to his brother who offers counsel and asks advice for the first time as a peer.

Next morning the police arrive to take both boys home where a heated confrontation with their parents sees David defending his brother and Ben taking charge of the family dispute. Over time, a more mature relationship is blossoming between the brothers, Ben entertains his new girlfriend and David pursues his talents.

This very grey English production focusses attention on the sibling of the person with intellectual disability and his attempts to reconcile his brother's needs with his own quest for adolescent independence. An interesting and well written drama where the character with Down syndrome stays in the background until the climax, then gently guides developments to a final understanding.

I was worried in the beginning that the show would be sugar sweet, then I was worried that it was going to be uncompromisingly dark and violent, then I was worried that Ben would be killed! I didn't want David to be a murderer either. Luckily, Ben's character was allowed to be amiable and feisty and contrary and observant. David had missed Ben's real character, seeing only the Down syndrome, not the brother or the person. This is an enjoyable tale without an insistently annoying moral ending but leaving the viewer with a satisfying confidence that the family are trying to work it out.

It had me thinking about whether those of us without intellectual disability actually take the real time to listen to our peers, friends, family members, to learn their depths, to accept their advice, to engage in life's difficult questions. Are we too busy coping to accept their help? Too busy guiding to be shown? Too busy teaching to learn?

The show offers a timely reminder to look after siblings, especially in adolescence, with the added consideration of growing up with a brother or sister with intellectual disability.

In this performance the uninitiated, ie the general public, see a different side of the disability story, one where the angst of the brother is the focus but also one which treats the person with intellectual disability with acceptance, dignity and respect, and eventually even allows them to lead..... ..