



NATIONAL COUNCIL OF WOMEN OF NEW ZEALAND

TE KAUNIHERA WAHINE O AOTEAROA

5 November 2012

S 12.32

Submission to the Ministry of Health on

Paying Family Carers to Provide Disability Support 2012

The National Council of Women of New Zealand (NCWNZ) is an umbrella organisation representing 47 organisations affiliated at national level and a further 41 organisations affiliated at branch level. It has 22 branches throughout the country attended by representatives of these organisations, as well as individual members. NCWNZ's function is to represent and promote the interests of New Zealand women through research, discussion and action. This submission has been prepared by the NCWNZ Family Affairs Standing Committee after consultation with the membership of NCWNZ.

NCWNZ has a long history of addressing the problems associated with people who live with a disability or have family caring for a member or members with a disability. In the NCWNZ submission S05.27 dated 30 May 2005, it was stated:

“Supporting people with chronic conditions in a holistic way has always been an important part of primary health care services. Such an approach is essential, as patients need to be able to access a range of services on an on-going basis to give them the best possible quality of life. They also need the support of family and the community. The patient and the support team require access to appropriate information, resources and financial support”.

NCWNZ membership is in agreement that there needs to be policy to deliver Ministry of Health-funded home and community support services to disabled people that does not discriminate on the basis of family status, and is based around the New Zealand Disability Strategy.

This Strategy presents a long- term plan for changing New Zealand from a disabling to a fully inclusive society.

- Create long-term support systems centred on the individual.
- Ensure the disabled person is at the centre of the service delivery.
- Value families, whanau and other people providing ongoing support to disabled people.

NCWNZ has ongoing policy dating from 1976, which supports the ongoing concerns the membership have in attempting to improve the status and quality of life for the disabled. Changes need to allow those disabled family members whose family homes are the best possible place for them to live, to be enabled to do so with the help of additional support for caregivers, who are or would be currently impacted financially because of their situation.

Equally important is to avoid families with less good will or skills using the proposed legislation to receive payment where the disabled member has less power and would

receive less skilled support that they would have in another living situation. The central issue in this matter appears to be how to maintain an appropriate balance where a family member is paid to provide care to a disabled person, so that neither the family member nor the disabled person is improperly incentivized or put in a position of vulnerability as a result of that payment.

Examples of internal conflict which may arise where a family member is the primary care giver for a disabled person might include:

- Opportunity costs – the caregivers may care for the disabled person at the cost of not pursuing some other employment that may or may not provide a good income.
- Family affection – the family may prefer that they provide the care because they feel that an outsider cannot provide the disabled member with the same level of affection and trustworthiness.
- Alleviating hardship – it costs to support someone who through no fault of their own is unable to contribute to the family income, which may be fairly stretched at the best of times.
- Family members should not feel pressured into having to care for other family members. It is important that all options rather than financial imperatives for best care scenarios are considered.

How can we ensure good outcomes for the disabled person and their family under a policy allowing family carers to be paid?

- There is strong support from the NCWNZ membership that there needs to be a case-by-case assessment of each family's circumstances and requirements.
- It should not be assumed that only family care will be provided. It may be that it is appropriate for some external caregivers/facility operators to be paid part-time and family caregivers to be paid part-time for split duties.
- In some cases after assessment it may be concluded that family care arrangements are not appropriate. In these situations, the assessment team involved should make it clear that where a good outcome for the disabled person and their family does not appear to be possible then funding will not be provided and external options will be considered. The interests and needs of the disabled person should be paramount.
- The family member must want to undertake the care-giving – not be coerced into it by other unwilling family members who see it as an opportunity to be relieved of any care-giving roles themselves.
- The family member who is willing to be the paid carer must be assessed on a case-by-case basis to determine through 'humanity testing' that he/she has the necessary skills, empathy, understanding of the disabled person's needs, patience and a genuine 'care' ability, in the same way that independent carers are assessed. Having a family member as the carer must not disadvantage the disabled person.
- The family member who is willing to be the paid carer must not be treated any less well in terms of payment than another carer providing a similar level of service. There should be holidays, with respite care, and provision for sickness.
- There needs to be opportunities for family members who are not in the same residence to take on the role of paid carer – this could be an adult son/daughter/sister/brother who has the appropriate empathy with the disabled

person. This then has the advantage of the main carer being able to undertake personal pursuits or other part time work.

- There will need to be a regular monitoring and review system established in tandem with the creation of a remuneration system. This system could be similar to that used to ensure that elderly patients have regular needs assessments.

It was noted by some of the membership that domestic violence of a disabled person by the primary carer, especially a spouse, and most commonly a male spouse, has been shown to be the result of fulltime/long-time care-giving without sufficient timeout for themselves. Tiredness, frustration about not having time for own pursuits, inability to cope, anger – all of these are experienced by fulltime and long term caregivers.

Should there be a requirement for disabled people to have independent support for planning and building networks before family carers can be paid?

- There should be an overall assessment and management plan drawn up on a case-by-case basis to determine the best and most appropriate source of paid care needed. The same requirements for an independent caregiver should apply to the paid family member and a contract prepared for signing by all parties. Factors that are directly relevant to this are:
 - The nature of the person's disability.
 - The likelihood of family care being successful.
 - Factors that limit the disabled person's access to non-family paid care.
- Some members thought that this should not be an obligatory requirement as in many cases this will not be necessary. These people will already be enrolled with at least one health provider so they can make a referral for independent planning if they think it is necessary.
- As circumstances are constantly changing, it is important that there are independent reviews done of the management plan based on the needs of those involved - especially if they are paid family caregivers - as well as those of the disabled person.
- Other support networks should be established to provide support for both the disabled person and the caregiver – these could include recreational/hobby outlets and those that provide specific support for the type of disability or illness that has resulted .
- Some NCWNZ members considered that if too many agencies were involved with the planning and establishing of the management plan, this could have a negative impact on the best outcomes.

How should new policy address the issue of quality and safety of the paid support received by disabled people?

- A specialist assessment, review and monitoring agency should be established which is dedicated to ensuring the optimum living situation for disabled people and to carry out regular monitoring.
- Members saw no difference between the issue of quality and safety whether the help came from outside the family or within.

- Caring in this specialized field requires training and it is important that all paid carers receive adequate and appropriate training. Also the home environment needs to be audited to make sure that the quality and safety of not only the disabled person, but the carers, are being maintained.
- There needs to be a case manager who would oversee and protect the carer from a disabled person prone to violence. The carer must have appropriate skills to manage such occasions.

The NCWNZ submission S05.27 agreed with the National Health Committee definition of self-management, i.e. *“people with chronic conditions having greater control in looking after themselves, (with the support of their families/whanau where desired), and in partnership with health professionals and community resources.”*

The same principles with self-management also apply to quality care for disabled people

- Empowerment is an important component of self-management.
- The programme needs to be tailor – made for each individual.
- A range of options should be available and the best one selected by or for the individual.
- Psychological support may be required to help a person to make an appropriate decision about the elements of self-management that could be beneficial.

It was also stated (and is still relevant when considering policy for disabled people), that in regard to advocacy services for those who are unable to speak for themselves, “ Advocates should have knowledge of entitlements and care should be taken to not unduly increase expectations of the person with a chronic condition.”

Should eligibility for payment be targeted?

There were varying opinions on this.

The majority of members though felt that eligibility for payment should be targeted, based on a needs assessment model.

- Eligibility for payment would go to those carers supporting disabled people in particular circumstances:
 - The remoteness of the disabled person’s residence making it difficult for non-family carers to provide support.
 - Specific cultural/religious requirements that cannot be met by an otherwise suitable carer.
 - The person being supported having high or complex needs.
 - There are significant risks to the safety and well-being of the person and/or family carers if family do not provide the support.
- It was suggested that eligibility be ‘phased in’. This would mean that those families that are assessed to be providing a very high level of necessary care would be funded first, with a gradual rollout to all families.
- Funding should be targeted on an ongoing basis, to ensure that those families that have the greatest need and fewest non-family options receive a proportionately higher amount of funding. Factors for consideration that were suggested included:
 - The level of care a family can provide without remuneration
 - The amount a family would require ensuring that both family and disabled person can live without undue hardship.

- Using a targeted approach carries a risk of arbitrary outcomes (or outcomes that are perceived to be arbitrary). The Ministry will need to ensure that any identified factors in targeting are robust and defensible.

Those members who were not in agreement with a targeted approach to paying a family caregiver, stressed that the principle of universality should apply. Means testing of the paid family carer should not apply as no person in the workforce is means-tested before they are paid to work, and eligibility should be the same for everyone when receiving state funding. The only form of eligibility used for targeting, should be to ensure that there is compatibility between disabled person and the family carer.

How should family caregivers be paid?

The members responses to this question where varied as to whether this should be Employment or an Allowance, and some felt that further research and analysis needs to be carried out in respect to these options.

- Family Carers should be paid for the number of hours of care provided based on that assessed for the person's needs.
- The familial relationship should not reduce what is deemed to be appropriate in terms of need assessment. Additional care, above and beyond assessed need, is likely to be provided in the same way as family members provide care in an outside caregiver situation. It's not 'paying' in the sense of a wage but is an allowance that recognizes that a family member is taking responsibilities which would otherwise need to be supplied by the Health Service.
- Affordability and sustainability are of course the key issues, so it is important not to raise expectations by likening this payment to a reimbursement for time spent on an hourly basis.
- There was agreement that the family member who is the assigned carer should be under contract to the Service Provider/Agency and receive the payment. This person would then be monitored by the Provider to see that correct care is provided and to ensure that the carer is accountable for his/her actions and provision of the type of care required. It also means that the one person who is paid is the one delivering the service, not a payment made to "the family" who may misuse the funding. If another person (e.g. cleaner) is employed, this cost should be taken into account when determining hours of work.

What should family carers be paid for?

- Training needs to be provided for all 'carers' whether they are family or not.
- The family needs to decide how much unpaid support they can provide.
- Each case should be dealt with on a case-by-case basis.
- Conditions of service/work undertaken by the carer should be covered by an evaluation of the needs of the disabled person.
- The family carer should undertake all personal requirements of the disabled person and this will depend on the level of disability. Small household duties that would normally be undertaken by the disabled person need to be considered and those deemed necessary should be included in the personal contract.

- OSH provisions have established duties not to be undertaken by independent carers and these would need to be considered by the contracting agency.
- Duties should be decided on a case-by-case basis with guidelines and rules provided for the safety and protection of both the client and the carer.
- Training is paramount for the carer whether it be the family member or an independent caregiver when medications are required by the disabled person.

Should a new family carers payment be established through the welfare system?

The majority of the membership was not in agreement with this for the following reasons:

- Any state funded payment should be seen as remuneration for work carried out, not a welfare benefit
- There are no safety measures or a caregiver support network in the Welfare System and there is little monitoring of services provided
- The preferred method is through the Ministry of Health, then through Service Providers with funding allocations to provide for independent carers of elderly and disabled persons. There is more accountability, and there are established networks and agencies.

The membership who were in agreement with this, cited the following reasons:

- Caring for disabled people who are not able to look after themselves, or need assistance, is a social responsibility.
- Payment through the welfare system would recognize the contribution family carers make in supporting disabled adults, rather than reimbursing them for providing home and community support services.

Some members felt that the payment system should have more than one component (option), be scalable, and provide choice and flexibility, while other members stated that simplicity is a good thing. The more complex the plan, the more confusion and opportunity to distort outcomes for the family concerned.

What do you see as the benefits and/or issues of recognizing the contribution of family carers through a family carers payment, administered through the welfare system?

- The current welfare system, which is undergoing significant reform at this time, may not be the best option.
- The payment system needs to be kept simple. Welfare systems may be too complex and generalized.
- The family member being paid as the carer needs to have a feeling of worthiness and recognition of the contribution to the family harmony and the possible prevention of domestic violence. They need remuneration rather than a welfare payment.
- Monitoring must ensure that the person being paid for care-giving must in actual fact be undertaking that role. If the contracted carer is unable to provide care at any time, the Provider/Agency must be contacted, so that another suitable carer can be assigned, as occurs with independent carers.

- The provision of a family carer's payment should not be at the expense of other essential services needed by the family.
- Families caring for disabled family members are managing situations that will require a great deal of tact and sensitivity on the part of the funding agency. Some members felt that within the Ministry of Health, a specialist provider should be established to deal with the special nature of these clients.
- Regardless of how payment is made, the worse-case scenario would be for the family carer to be put in a position to have to continually justify their case to receive payment.
- Some members suggested that there should be a 'cap' on the amount available to pay family carers and /or only paying family carers in particular high need situations.

Hard Choices: Should the increase costs be funded from within the funding that is already allocated to disability support?

NCWNZ members have stated that additional funding will be required.

- It was suggested that sufficient funding could be prioritized (particularly if the tiered approach to implementation was adopted) from within existing Government budgets.
- Reviews need to be undertaken of all systems to ensure all are delivering services as required and contracted.

Allowing family members to provide disability support for the long term will require long term support systems being centred on the individual.

Important factors when considering how this could be achieved to support the families to achieve this are:

- Managing the economic cost and administrative burden of the new regime in the most efficient way possible. The disabled person's needs is the most important issue and they should be receiving the best care that is available.
- Ensuring proper training, monitoring and specialist input is provided to protect the interests of both the family carer and the disabled person.
- Employing family carers through an established provider of home health services, would provide the family carers the same entitlements and support as any other person using these providers.
- It must recognize the validity of both prior and existing situations where family members have been giving totally safe and quality care to their relative for many years already.
- Recognise the valuable contribution carers make. Many carers make personal sacrifices, financially and socially, and financial help would help to alleviate these.
- There is a need to guard against a culture of suspicion that expects everyone to be rorting a system when only a very small number do so.

Conclusion

There is only one outcome that should be considered for Family Carers to Provide Disability Support – a better outcome for all involved.

Unpaid family and community support are important, but it is unrealistic in some circumstances to expect such support to be available in all cases. Families should not be placed at a disadvantage by having to provide a significant degree of unpaid support to disabled persons who have high needs or who have specific requirements that cannot be met by available paid support. It has also been noted that in the case of a disabled person's condition deteriorating and home-based care-giving is no longer appropriate or suitable, it may be necessary to consider institutional care. This is especially difficult for those who are not 'aged' as there is little suitable institutional care for those under 65 years of age.

There needs to be a long term commitment and secure funding for this new policy so that the New Zealand Disability Strategic Directions can be upheld.

Establishing the appropriate ratio of providing paid and unpaid family carer support for a disabled member is complex and challenging. This present consultation document will most likely raise a significant number of further issues which will require further consideration. The indicative timeline proposed does not indicate that further consultation will take place, so we urge the Ministry to reconsider this.

Barbara Arnold
President NCWNZ

Billa Field
Convener, Family Affairs Standing Committee