

# Translating research into action

The interface between informal and formal carers: A critical examination of a government-driven initiative in light of research findings

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# Background





# Informal caring

*Informal caregivers are those who care for a friend, family member or neighbour who because of sickness, frailty or disability, can't manage everyday living without help or support.*

- ☀ Informal caregivers are not generally paid, or subject to any formal agreement.*
- ☀ Informal care giving refers to ongoing care rather than care for a brief illness or disability.*

*As defined by the National Health committee*



# Our study



☀️ Funded by the National Health Committee (NHC)

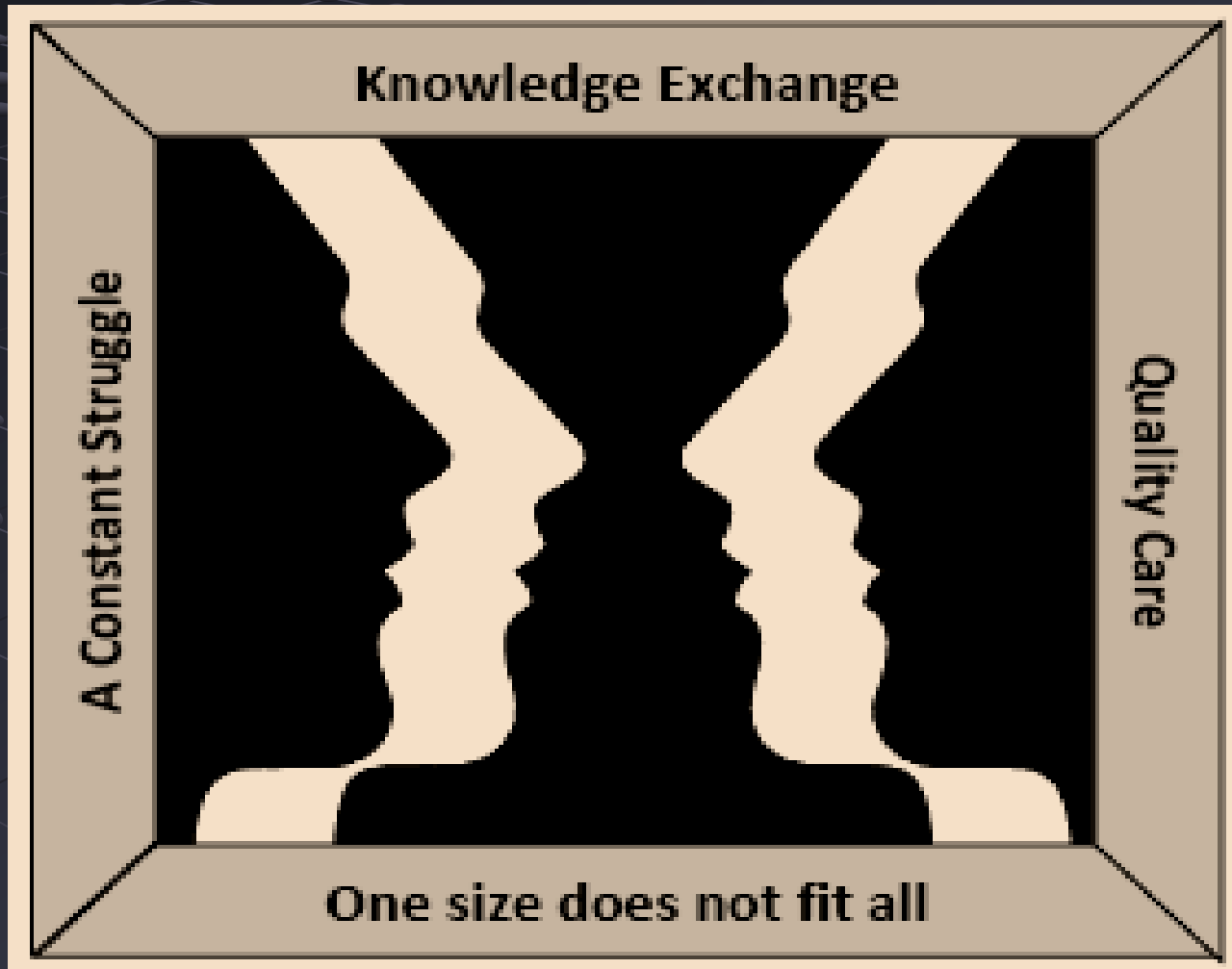
☀️ Aimed to:

Explore the interface between formal and informal care giving; and Identify how formal services can better support informal carers.

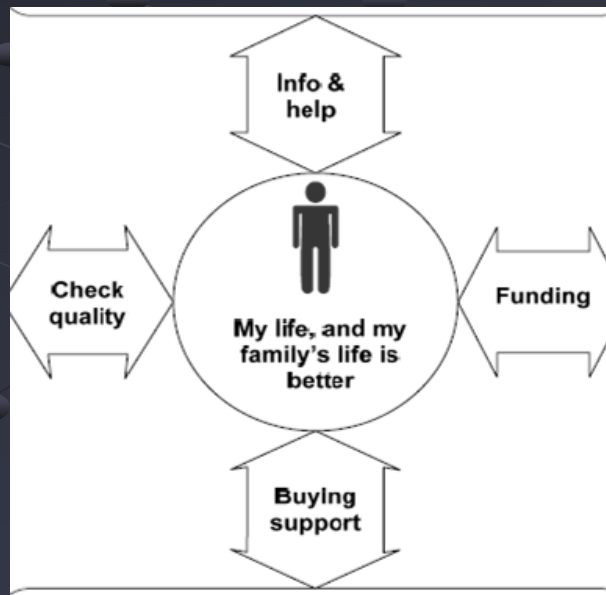
☀️ Qualitative study

- 13 focus groups
- 22 individual interviews
- a total of 70 participants
- with informal carers, formal service providers and carer advocates.

# Findings

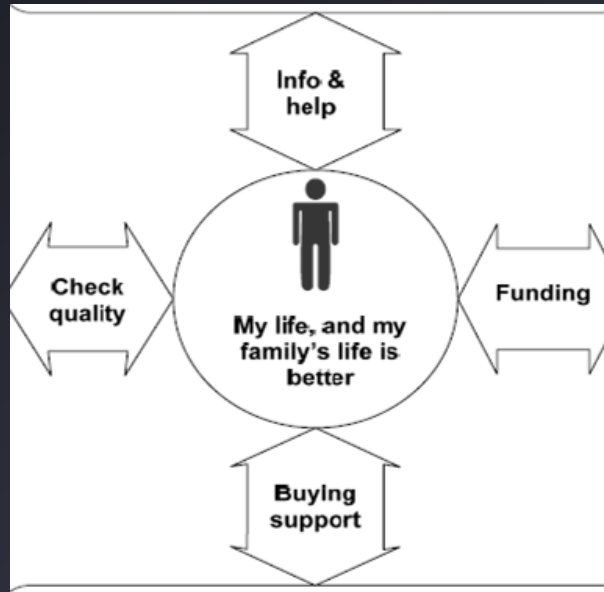


# Will the new model for supporting disabled people address the issues raised by carers?



Local area co-ordinator

Accountability  
arrangements



Individualised  
funding

Increased choice and  
control

# Local area coordinators

To walk along side the disabled person and help them work out what they want from life help them build community networks

- ☀ Provide personalised information
- ☀ Develop and access family and community support
- ☀ Help with accessing government funded services and disability supports



# Knowledge Exchange

They ...need information about other community services available...information about the mental health system itself is quite a complex thing ...it's very difficult for families to know ... this whole system the lay of the land...there's all these different types of services that are either government and non-government and there's all these other networks that are woven into this there's all sorts of things going on and families often need to know so they can navigate it and get the best out of it and be aware of the services that are there for them to use

(Mental Health carer advocate)



# A constant struggle

We had a go at (NASC)... a lovely guy on the phone but we have the same conversation on the phone six times he asks the same questions each time and goes back over the old ground, he was doing the paper work for the ( service ) ... it was a nightmare and my wife broke down in the end she couldn't handle it because she is really good and normally handles all that but it just got to a stage where I had to go into catch up mode and take over because it just stopped and she was in tears

(MS carer)



# One size does not fit all

There was this old guy ... his wife is a paraplegic and she is at home with the bed with all the bells and whistles the electric bed the whole bit, which is really helpful - and he has a camp stretcher in the room that has been set up for her which he sleeps on in case she needs him during the night..., he's 88 and ... there are people in and out – physios going in to her and the district nurse and home support workers **and nobody has ever said to him “look I wonder if we could organise a proper bed in here for you”** (Informal carer and Carer advocate)



# But ?

- ✿ Building natural supports ?
- ✿ How much support will be available for those providing the informal care?
- ✿ Where does the informal carer stand?
- ✿ How many people can the LAC Walk along side?



# Individualised funding

Moving towards giving funding rather than services and offering self assessments

- ☀ Resource allocation rather than service allocation
- ☀ Self assessments with less professional assessments
- ☀ More choice and control over services
- ☀ Clearly defined rules

# One size does not fit all

Had we been given the choice to decide how we could spend our respite in our time - with our daughter we would have probably involved extended family a lot more, ... that's not cheating, that's actually using the respite system that best meets the needs of the family .... Mum and Dad, and that flexibility isn't there.... Families should be given as much autonomy to make these decisions for themselves ( Informal carer and Carer advocate)



# One size does not fit all

I say look he's got autism and he's got deafness – you've got to work together he can't get shunted here shunted there – he can't fit this box he can't fit that box he's got both boxes.... There is so much inflexibility and the whole thing about the case to case thing; they are so rigid that they don't see your individual family circumstances. They just don't.  
(Parents of children with mixed disabilities group)



# Constant struggle

I don't know what is available, ... a friend seems to think that once I get the ball rolling with the doctor it could take three months of paper work to go through ... I have to nominate a person that can come and look after him...well I wouldn't have a clue who that would be

(Stroke carers group)





# How much more choice?

- ☀ Will there be help available to manage their own services?
- ☀ Funding is to allocated after accounting for available natural support what will this mean ?
- ☀ Responsive assessments

# Stronger accountability arrangements

Better ways to check that people are having a good life

- ☀ Checks the disabled person, support providers and the Ministry
- ☀ live everyday lives,
- ☀ meeting responsibilities
- ☀ value for money

# Quality care

*I really think the only real care can only come from the partner, but ...being realistic ... I can't live like that so I compromise all the time to try to see that he has all his needs met and I know that I can do it, but aging as well, I'm 70 now and I have my own incapacities to deal with....he was coming to the (service), which meant that I had the house to myself..., what bliss that was, absolutely marvelous, ... but the thing is that ... we've dropped the (service) I accepted that, you can't force him in, ... changes happen, we had tension over the weekend and I said, don't go*

(Palliative care group)



# Is it a good life?

- ☀ What is a good life?
- ☀ How will it be assessed?
- ☀ Will accountability mean more paper work ?



## **The new model**

**Information and  
assistance -  
coordinator**

**Allocation of  
funding**

**Flexible options**

**Increased  
accountability**

## **Our study**



**Responsive needs  
based assessment**

**Services that fit and  
care see carer and  
cared for as unit**

**Competent  
consistent care**

**Two way knowledge  
exchange**

# Knowledge Exchange

They haven't asked our opinion or asked about what's going on at all, ... they don't actually check back to see well actually what is going on here? So you feel quite often as a care giver that you are not what's the word? you're going through the experience of doing the looking after and helping and sustaining or whatever but it's a question of acknowledgement it's more a question of your experience of it and of what the progress is – it's not taken into account and that's a problem, it's a pity because I think they are missing out on something.  
(Informal carer)



# A way forward ?



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