



Leveraging social investment

Young People in Nursing Homes Alliance

Imagine you're only 21 years old, you may be studying, travelling or working, your future lies ahead. Then the unthinkable happens, and you end up with an Acquired Brain Injury, with no compensation payable, or are diagnosed with a degenerative condition such as MS, Muscular Dystrophy or Parkinsons disease. Your condition will require 'round the clock' care and your family are told one of the only options available is to put you in a nursing home. Yes, a nursing home full of elderly people who are winding up their lives and are too old and frail to look after themselves – hardly the place for a young person is it? The frightening thing is there's currently around 6,500 young Australians in this situation with numbers increasing every year.

Back in 2002, it came to our attention that thousands of young people with Acquired Brain Injury (ABI) or progressive degenerative conditions, such as MS, were living in nursing homes set up for aged care, so they were not receiving the care or rehabilitation that their conditions required, and as members of our community, they should be entitled to.

Through discussion with our contacts and networks in the Not-for-Profit sector, we came to understand that the cause of this terrible situation was related to a government structural issue. State Governments have responsibility for funding disability and the Federal Government has responsibility for funding nursing homes, but neither was really taking responsibility to see that these young people received appropriate care.

To ensure we had a complete understanding of the situation and be confident the appropriate strategic approach would be undertaken to ending this impasse between tiers of government, we held discussions with Melbourne City Mission, and a consortium of organisations including 'Headway'.

In 2002 ANZ Trustees provided funding for a one-day National Summit that brought together interested organisations, individuals (consumers) and government representatives to discuss approaches and jointly form a "Call to Action" to the two levels of government. From that meeting grew the Young People In Nursing Homes Project (YPINH). We funded YPINH to research the needs, to collect data on those affected, and to mobilise the energy and anger that the families who were despairing of the plight of their children felt, and direct this passion where it would have the most effect.

ANZ Trustees and the WCF Thomas Charitable Trust (for which we are a co-trustee) provided \$148,200 in funding for the YPINH project in 2002 and 2003. The majority of the funds coming from WCF Thomas, which has a national reach. Another trust outside of ANZ Trustees, the John T Reid Trust, has contributed to fund the advocacy part of the work in recent years. The YPINH Project is now the YPINH Alliance.



YPINH developed a successful campaign that ensured their cause generated the attention and support to become one of the highest profile disability issues. As a result of the wonderful leadership of those involved in this project, especially the untiring efforts of Dr Bronwyn Morkham, the project manager, the Federal & State Governments (COAG) made an announcement recently that they would jointly contribute \$250 million over five years to redress this unacceptable situation. This is a historic and much celebrated agreement.

The funds will be used to:

- provide capital for new appropriate facilities that are purpose run
- provide ongoing services for this group
- conduct assessments on individuals
- fund transition costs
- provide individualised counselling to assist people to determine what type of care they want, and then provide funds to support that care.

Following is an extract from an email received early March from Dr Bronwyn Morkham:

Dear Teresa

It was terrific to see you on Wednesday!! As I said then, we were able to be there at all because of the support the philanthropic sector has provided to develop a campaign around this longstanding issue and ultimately get Federal and State Governments to act.

I am particularly mindful of the fact that ANZ Trustees, through the WCF Thomas Charitable Trust particularly, was the first to recognise the imperative to do so and had the faith to provide much needed funds to the YPINH Project to begin this work.

In the 3½ years since, we have developed what has been acknowledged as one of the most professionally run and successful campaigns the disability sector has seen and established the YPINH issue as the pre-eminent disability issue of the day. Along the way, we have achieved all but one of the desired outcomes expressed in the *Call to Action* agreed to by stakeholders at the National Summit in 2002

The Project's groundwork has enabled the Alliance to become the key consumer peak body, both nationally and within each State. We will be directly involved in the implementation of the COAG initiative at all levels. As well as maintaining vigilance around implementation of this initiative and working with governments at all levels to ensure its success, the Alliance will be working with both tiers of government to further expand this program so that *all* young people living in aged care facilities have a choice about where they live and how they are supported. The COAG initiative is very clearly a first step to deliver these supports to all YPINH. The Alliance's job will be to make sure that all 6½ thousand young Australians have that opportunity.

For further information on YPINH and their current activities, you can visit their website:

<http://www.ypinh.org.au>