Chronic Illness Alliance

Keeping us in the loop: the contribution of the Not-for-Profit sector to the economy, health and disability systems and all those it serves

A discussion paper

"Don't it always seem to go
That you don't know what you've got
'Till it's gone
They paved paradise
And they put up a parking lot"
Big Yellow Taxi Joni Mitchell 1970

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EXECUTIVE SUMMARY

- Not-for-Profits (NFPs) are under threat in terms of funding and their charitable status from both State and Federal Governments
- Some are also losing block grants from State Governments due to the NDIS
- There is widespread misunderstanding that those individuals – people with chronic illnesses, people with chronic illnesses and/or disabilities who are employed, older people, the newly diagnosed – still need information and services to manage their health and well-being, but are not eligible to receive NDIS services
- The information and services they require is often highly specialised
- There are suggestions that assaults on the NFPs are driven by governments' adoption of neo-liberal economic policies which favour the establishment of for-profit industries
- We address the assumptions that for-profits will be of greater benefit to people with chronic illnesses and/or disabilities than not-for-profits
- It is important that the community, governments and bureaucracies and those who use the services of the NFPs better understand the impacts of not supporting NFPs as a valued feature of our society. This includes their contributions to
    - the economy
    - reducing health costs
    - health promotion and primary and secondary prevention activities
    - funding of medical research
    - advice on health policies and health services

- Loss of NFPs means that for-profits will replace the specialised services they offer with homogenised services delivered by less well-trained staff in order to maximise profits
- While mergers and partnerships are suggested as the means to deal with these threats, we suggest a NFP group modelled on successful industry groups be developed and that work be undertaken to ensure the community and all others understand the full impact of moves towards privatisation

1. INTRODUCTION

The Disability Advocacy Alliance located in NSW launched a petition on change.org in late 2017 requesting the NSW Premier continue funding advocacy organisations. The petition argues that people with a disability require advocacy assistance to obtain information, representation and advocacy. Further, the petition cites examples of the Victorian and Federal government continuing to fund 'advocacy' organisations while NSW will not. However, from 2019 the Victorian government will start to withdraw funding from those Not for Profits (NFPs) it currently funds. These changes by State departments relate to the introduction of the NDIS.

The Guardian reported in October 2017 (1) "The NSW government is putting the responsibility for disability advocacy with the National Disability Insurance Scheme (NDIS)". Disability advocacy groups across the country are facing closure as states withdraw funding ahead of the transition to the national disability insurance scheme.(2) The sector is warning the cuts threaten to leave "huge gaps" in representation for the rights and interests of people with a disability, at a time when it is most needed. Most states and territories plan to withdraw their long-standing funding of disability advocacy as part of the NDIS rollout, but the scheme itself does not properly replace advocacy funding.

This discussion paper analyses current funding problems for Australian Not for Profits (NFPs) with the aim of offering some solutions.

In this paper we concentrate on those NFPs that are community-based and largely began as specialist organisations to support people who were not always well served by the health and disability systems. While hospitals and other health services are also NFPs, their funding, though sometimes subject to cuts, is far more certain. Along with primary health services they are seen as central to the health system. Specialist NFPs receive funds from a variety of sources including donations, bequests, fundraising activities, project grants and volunteerism. More NFPs now offer fee-based training. Amounts from these sources can be very variable. Block funding from governments including state and Federal, is important to NFPs and assists NFPs to budget with some certainty, though not all NFPs receive it. Block funding is often directed to providing information and counselling to individuals.

Most recently States have begun withdrawing their block funding from NFPs on the basis that services will now be funded through the NDIS. NFPs are expected to compete with for-profit agencies offering services to clients as part of their packages. Many NFPs do not have resources (3) to set themselves up to compete for services when sources of funding are being withdrawn.

The context of neoliberal economics which drives the creation of for profit industries, State-Federal relations and the NDIS has created a paradoxical situation. The NDIS, designed to empower people with a disability, is leading to a loss of funding for organisations that contribute to that empowerment by providing crucial information and assistance, and advocating on their behalf.

The funding reduction also comes at a pivotal period of disruption in the disability sector, when individuals most need information and support (4).

At this point it is important to emphasise that funding for many NFPs provides information services for those who are newly diagnosed, perhaps able to return to work and/or in need of rehabilitation as well as those who are minimally disabled and not eligible for NDIS services. NFPs provide information aimed at secondary prevention which has the potential to reduce unplanned hospital admissions and long-term disabilities and comorbidities, as well as working with highly specialised

conditions. Another important aspect of NFP services is building community awareness to prevent stigma and to alert the public on many preventable conditions associated with risky behaviours.

The Councils of Social Service reports: "In the ACT the launch of the NDIS has led to government withdrawing from the provision of services in some areas (specifically early childhood intervention, and residential homes). But the ACT Government has now recognised it cannot do that without first developing the markets intended but not yet in existence. They have also recognised a need to continue to provide block-funding for Tier 2 services that are not commensurate with the individualised funding model and to ensure that those people who are not eligible for the NDIS are able to access needed services." (5)

The example below illustrates how changes to block funding for a NFP will impact on supply of information and support to people who are unlikely to qualify for NDIS funds but nevertheless need such assistance.

Epilepsy Foundation:
Department of Health and Human Services (DHHS) disability funding enables Epilepsy Foundation (EF) to operate a crucial state-wide information and support service for people living with epilepsy (PLWE) and key stakeholders. However, the National Disability Insurance Scheme (NDIS) has changed the playing field and presents EF with significant challenges as a specialist neurological community organisation.

When the full rollout of the NDIS occurs in July 2019, $1.2 million of DHHS recurring funding will be removed from EF and transferred to the NDIS. We aim to earn some of this back by providing services to NDIS participants with epilepsy. There are approximately 50,000 PLWE in Victoria. The EF has a long history of providing extensive support to Victorians with epilepsy; however, only 20% of EF clients may be eligible for NDIS funding. Thousands of Victorians are at risk of losing much needed health information and support because of a lack of alternative funding options to replace the funds being withdrawn. This number will only increase as the population ages, due to the higher prevalence of epilepsy, often undiagnosed, in those over 65 years of age.(6)

In fact, NFPs underpin the NDIS and with adequate funding to deliver timely information and support can work to prevent increasing numbers of people with disabilities accessing its services or in those cases of inevitable condition progression delay that access. This view is partly supported by recent research on the role of pricing of NDIS services, described below. As we have seen, they provide services to people who are not eligible for NDIS funding but in need of other services due to their conditions.

If the National Disability Insurance Scheme (NDIS) is going to deliver, it will have to adjust its pricing model, writes University of Western Australia Professor David Gilchrist following the launch of the second report of the National Disability Benchmarking study.

The NDIS is a critical part of the Australian disability system but it is not the entire system. If the economics of the NDIS are not fixed, including in relation to the roll out of the new scheme, then another important part of the Australian disability system — the service providers — will likely collapse or withdraw from disability service delivery. Of course, the risk here is borne by the service users who rely on disability service providers to support them in their everyday lives.

Over the past two years, Penny Knight and I have worked with National Disability Services (NDS) to examine the sustainability of the disability services sector. The primary driver for this examination has been the advent of the NDIS; however, last year we reported that there was a significant minority of not-for-profit disability services providers that were subject to considerable financial stress prior to participating in the NDIS. This year, we have confirmed that this cohort continues to struggle financially and are concerned that, as the NDIS rolls out more fully, collapse of many of these organisations may occur or they may simply withdraw from disability service delivery.

The research undertaken is based on the 2014/15 and 2015/16 financial years and follows a panel of 180 disability providers nationally, ranging from large Australia-wide organisations through to smaller niche or local players. UWA's longitudinal research approach plays an important role in monitoring the transformation of the sector. Key findings of the report also include a decline of panel members' rating of their own organisation's financial performance and declining optimism in future financial survival.

The research, which has informed the Australian Productivity Commission in its recent review of the NDIS and its current pricing structures, aims to assist in facilitating the development of policy that fosters a strong and efficient supply of disability services and supports the achievement of the objectives of the NDIS. Indeed, the importance of this work has led the Productivity Commission to recommend that the study be continued.

In short, this research aims to provide government, service providers and the broader community with detailed information on the supply and sustainability of disability services in Australia. We have identified that if the NDIS is going to deliver, it will have to adjust its pricing model. While many of these organisations are reporting that they are profitable, this profitability is declining and disability services organisations rely heavily on donations and bequests to balance their books.

Indeed, without donations and bequests, profitability is virtually extinguished in the aggregate. Further, many of these organisations also provide human services (such as aged care) in addition to their disability services and the lack of profitability in their disability services operations may lead many to abandon the provision of these services in order to reduce financial risk to the remaining mission-centric activities they undertake. Thus, poor pricing under the NDIS might incentivise providers to drop their disability services rather than risk financial calamity.

While organisational respondents fully support the potential of the NDIS policy, many are experiencing financial stress and concern about the viability of their disability services and do not expect to meet demand for services in 2016/17.

The key question for government policy makers is whether the sector has sufficient, suitable and available assets to fund the change. Further, it is questionable whether it has sufficient change management capacity, and if there is enough incentive to encourage the level of investment needed to build the sector in this context. In other words, the roll out of the NDIS is not subject to an industry plan nor is there adequate co-operation between disability service providers and the NDIA which would allow for a balanced, certain and sustainable NDIS in the interest of service users.

About the author: Dr David Gilchrist is a chartered accountant and an economic historian. He holds a PhD in economics from the University of Notre Dame Australia and is currently professor of accounting at the University of Western Australia. He was foundation director of the Curtin Not-for-Profit Initiative for five years. He currently holds a number of industry roles including Chairman of Nulsen Disability Services, a director of Baxter Lawley Advisory, a member of Chartered Accountants Australia and New Zealand's National Not-for-Profit Advisory Committee, a member of the Australian Charities and Not-for-profits Commission Advisory Board and of the Australian Accounting Standards Board Academic Advisory Panel. (7)

The comment above by Dr David Gilchrist suggests that part of the problem lies with poor understanding of the role of NFPs. This in turn is compounded by:

- Sources of funding of NFPs
  Which government department fund NFPs to work with people with disabilities or health conditions may be largely historical rather than based on a diagnostic distinction. Or it may be related to policy initiatives. In some instances, a NFP will receive government funding from a disability department and other NFPs will receive their funding from the health department or through a government department specialising in mental health, or ageing. This has created a false division between disability, mental health and physical health conditions whereas the lived experience of people with health conditions is that many can develop a disability associated with the health condition while those with disabilities may develop a chronic condition. While this has been largely resolved within the NDIS as eligibility is based on the severity of any disability, it has not been resolved for the funding of health conditions and less severe disability requiring information and support.

- Poor data analysis and evaluation of the contributions of NFPs to both the health and disability sectors
  Annual reports demonstrate that most health-related NFPs report the number of services they provide to clients and the community. Services include individual support and information, family and carer support and education, case management, community and schools education, awareness raising and research initiatives. Data is collected recording numbers and hours of services provided, miles travelled, information packs and resources such as equipment provided and geographical reach. More recently, data on interactions over websites and social media are also included. However, the impacts of this work on the quality of life of individuals and family and carers or on medical and disability services are rarely analysed. This lack of evidence makes it easier for politicians and government departments to treat NFPs as an expensive 'sideshow'.

This viewpoint is corroborated by a Councils of Social Services (COSS) 2014 submission on competition policy, which argues that overarching government competition policies undermine the models of community partnerships fostered by NFPs. Principles of competition policy now drive the funding of community organisations such as health and disability NFPs (COSS, p3). Further, in its submission COSS pointed out the Government's intention to withdraw funding in order to increase competition: "The Inquiry's terms of reference state that 'government should not be a substitute for the private sector where markets are, or can, function effectively or where contestability can be realised" (COSS p4).

There are a number of challenges in reconciling competition policy with the role of community organisations in supporting community health and wellbeing. ***The central challenge is how to foster principles of competition in an environment that is, at its core, about relationships.*** *Given that community organisations have often sprung from, and for, their communities, and that the needs identified and the supports to meet them can be highly complex and personal, relationships of trust and understanding are absolutely central to the work and value provided by community organisations. Where these problems are not just complex but integrated, and where resources are never sufficient to meet need, collaboration is an equally important strategy in effectively meeting needs and supporting people and communities.*

None of these central tenets of community organising sit comfortably with the principles of competition: indeed, many within our networks argue that they are directly contradictory. For example, the evaluation of the Communities for Children long-term, place-based initiative found positive impacts based on:

- *a partnership model;*
- *funding to support the work;*
- *a strong community outcomes focus resulting in a greater number of services based on the needs of the community;*
- *better coordination of services; and*
- *a focus on improving community "child-friendliness" (that is, community "embeddedness", or social capital).*

Increased competition is likely to undermine the success of partnership-based, community focused and integrated service models. (5)

In some respects the implementation of competition policy in these community service areas amounts to a cost-shifting exercise. ACOSS reports that those not eligible for the NDIS such as people with chronic health needs are expected to access information and support through the education and health system, but this is not serving them. In fact, most people with chronic health needs who are moderately disabled always sought these services from the dedicated NFPs **because** the education and health systems failed them in this respect (COSS p10).

Below is an example from the Victorian Aboriginal Community Controlled Health Organisations (VACCHO) arguing that the pricing of NDIS services will not adequately serve aboriginal people with disabilities since this pricing does not recognise the level of complexity including cultural issues. Competitive markets will not provide the level of services required in what has been identified as 'thin' markets, that is, in those populations requiring specialist services where there are low numbers of buyers and sellers, for example rare conditions or where services are spread across rural and regional areas. Such markets mean higher overheads and lower profits. Block funding provides people serviced in thin markets with information about their rights to services.

VACCHO Submission to NDIS Independent Pricing Review
In this submission the Victorian Aboriginal Community Controlled Health Organisations (VACCHO) argue that the pricing of NDIS services will not adequately serve aboriginal people with disabilities since this pricing does not recognise the level of complexity including cultural issues. Competitive markets will not provide the level of services required in what has been identified as a 'thin' market that is, in those populations where existing services are already poor, underdeveloped and spread across rural and regional areas.

"Block funding to ACCHOs may be the best avenue to provide some of this support (e.g. community engagement, cultural support workers and investment in infrastructure), as well as a mechanism to support ACCHOs which are unable to break even while servicing a thin market."

"VACCHO is highly concerned about the short and long term impacts on people who are entitled to, but will never, receive a package under the scheme, as well as the participants with a plan that does not meet their needs. Funding is needed for the ACCHOs to provide community information and engagement, support to access assessments and complete the paperwork required, as well as support to attend the planning meetings and subsequent reviews." (8)

2. CONTRIBUTIONS OF NFPS TO THE AUSTRALIAN ECONOMY, THE HEALTH SECTOR AND GOVERNMENTS AND BUREAUCRACY

2.1 Economic Contribution

It is difficult to separate out those NFPs working in the different sectors. However, Deloitte Access Economics (November 2017) attempted this with ACNC data for 2014-15. When talking about the health sector, it should be noted that this includes hospitals and health services with charitable status.

The overall charity sector is a major contributor to the Australian economy. The economic contribution of the 55,000 registered charities is estimated by Deloitte Access Economics at $129 billion, comprising $71.8 billion direct contribution and a further $57 billion flow-on contribution. The sector directly employs 840,500 full time equivalent (FTE) paid workers, and its associated activities leads to a further 471,700 FTE workers being indirectly employed.

This means the sector is roughly equivalent in size to the Australian retail sector, education and training, or the public administration and safety sector. Additionally, formal volunteers are estimated to contribute 328 million unpaid volunteering hours, costing around $12.8 billion in wages, if paid, to hire (Deloittes Access Economics Nov 2017). While a large proportion of charities (over two thirds) reported no staff, the health sector accounted for 30% of the total sector employment. As well, the total value-add from the health sector was over $31 billion.

Sources of income in the charity sector are donations, government grants and other (such as sales). Within the health sector donations are a relatively small proportion, probably reflecting the hospital sector which relies on Government funding.

2.2 The role of NFPs in reducing health costs

We argue that NFPs contribute to reducing health costs in the following areas.

2.2.1 Health literacy

NFPs assist with developing the health literacy of Australian consumers. This begins when NFP client services speak with newly diagnosed people, often too emotionally fragile to have fully understood the information delivered by their health professional. It continues in any phone or face-to-face counselling role or when the consumer requires a higher level of information to assist them managing their condition, seeking appropriate services and printed information. It is further cemented by NFPs providing additional opportunities to develop health literacy through information evenings, peer support groups, school presentations and weekend camps. Much of the NFP work in this area extends beyond the patient to the family and communities. When NFP funding is reduced, their capacity to work in this area becomes significantly diminished.

Health literacy is identified as a crucial component of good health outcomes. The Australian Commission on Safety and Quality in Health Care (ACSQHC) argues that health literacy needs to be embedded into the health system and that its successful implementation depends on partnerships with consumers. (9)

Otherwise, low levels of health literacy are associated with poorer health, higher rates of hospitalisation increased use of emergency departments, medication errors and poorer self-management of chronic conditions (Berkman et al 2011; ACSQHC 2014. (10)

In 2006 the ABS concluded that 59% of Australians were functionally health illiterate with those who spoke English as a second language far worse off than those whose first language was English. This situation may not have improved. Given the low level of health literacy and that there is no dedicated approach to address it, both health consumers and health services need all the help they can get!

Reduced funding for NFPs reduces their ability to contribute and may ensure increased inappropriate use of health services. However, there is little research undertaken on how much NFPs contribute to health literacy, though research about health literacy indicates an association between health literacy and preventable hospitalisation rates. (11)

2.2.2 Contributions to health promotion and prevention activities

NFPs make significant contributions to health promotion activities. Most NFPs offer advice on screening, on good nutrition and exercise. Examples of this are the state-based cancer councils, national heart foundation, state based diabetes foundations and arthritis foundations. Along with advice on primary prevention, there is similar advice on secondary prevention activities. One valuable example of this is work undertaken by Epilepsy Australia in researching and developing information on sudden unexplained death in epilepsy (SUDEP), an area that was previously considered insignificant (12, 13).

Another example relates to mental health promotion. Activities identified relating to mental health promotion are support and services, information provision, activities and advocacy. They are often delivered by volunteers. Boyle et al acknowledge that NFPs are well placed to assist people with mental health conditions develop resilience in the face of disability and other problems (14).

2.2.3 NFPs make substantial contributions to medical research funding

Because NFPs work with distressed consumers whose principal interest is finding a cure for their condition – if not for them, then for those who come after them – many NFPs also raise funds for medical research. Examples are the many foundations working with cancers, such as breast and ovarian cancers. The Bowel Cancer Research Foundation is another major example with funding going to a Chair of Bowel Cancer Research at Sydney University as well as funding for clinical trials and community awareness research. (15)

These research funds may be substantial, as for example the MS Research Australia where some $37 million has been raised since its inception. MS research funds support sophisticated medical research and health improvement research at academic institutions and health services for people with MS (16).

It is worth noting that in promoting research and seeking donations to support it, these NFPs raise awareness of the issues in the community. The example of bowel cancer research funds shows the related prevention, testing and support available freely to people on its website.

NFPs unable to fundraise for research projects contribute to research interests by promoting clinical trials and research projects, calling for people to volunteer to be part of the research. Most NFPs promote research findings by inviting researchers to present

at community events and AGMs. This is important to funders who now want to see the research communicated to a wide audience.

2.2.4 Contributions to health policies and health services

NFPs contribute their knowledge, time and energy to the development of policies and health services, by participating in advisory committees, presenting at Senate subcommittee enquiries and sharing their work with departmental staff. Most of this contribution is at the NFP expense.

Many NFPs are the repositories of highly specialised information on rare, serious and unusual conditions which they share in order to design appropriate services and policies at health services. Examples of this include MS, haemophilia, thalassaemia, the epilepsies and rare cancers. Cystic Fibrosis Victoria worked closely with the Alfred Hospital and Royal Children's Hospital Victoria to ensure that young people with cystic fibrosis were not lost to health care in the transition from paediatric care to adult care. The work of HIV/AIDS organisations both in Australia and internationally demonstrates how significant such contributions continue to be (17).

Other NFPs have advocated on behalf of indigenous people, people from low socio-economic status, CALD backgrounds and people from LGBTIQ backgrounds for more suitable and safe services. In many instances, such advocacy has changed the face of policies and service delivery.

Many consumers arrive at health or welfare services having been 'prepped' with advice and relevant information at a NFP, often saving health professionals and departmental staff valuable time.

2.2.5 Peer support and self-management programs

Peer support takes place when people who are living with the same or similar illnesses share their time and experiences with each other to offer hope, encouragement, self-management strategies and a positive role model. NFPs foster peer support through support groups, community events, information evenings and condition-specific camps and weekend workshops. It is a cost-effective means to deliver education and also has outcomes of increasing health literacy, improving self-efficacy and a place to support others which may assist in reducing comorbid depression. The evidence base for peer support is slowly improving, largely through better-designed and evaluated peer support programs such as those undertaken by Peers for Progress in the US (18).

Self-management programs have always been delivered by NFPs though programs to assist people with cardiovascular diseases and associated conditions, and these are now more widely spread through hospital and community health services. Those self-management programs delivered by NFPs have the advantage of placing ill and recovering people in a program in their community which helps them to revitalise their everyday lives.

2.3 Concluding remarks

We have articulated the contribution of NFPs to the economy and health services because their contributions are taken for granted by health and disability services in government departments and by others. To some extent, they are so endemic to community lives their existence is forgotten.

These activities of health literacy, health promotion and prevention activities, research funding, working with policies and services and peer support activities contribute substantially to the health system. If we take these, together with the economic contribution of NFPs to the Australian economy through employment and volunteerism, then their removal may have a extensive impact on the health system and the economy. The underlying problem is that these activities and their wider contributions are not evaluated (19).

3. ENCROACHING PRIVATISATION

3.1 '*we won't know what we've got until it's gone*'

This discussion paper began by discussing the loss of departmental block funding and the growing need for NFPs to compete with for-profit NDIS services. Because the contributions of the NFP system (excluding public hospitals and community health services) are neither acknowledged nor effectively evaluated, increasing encroachment of private enterprise into its work is deemed as opening up new markets. This may produce both socially and economically unacceptable outcomes.

Australian consumers already know that privatisation of utilities has not delivered cheaper electricity, with costs of electricity being triple that of overall costs between 1997 and 2016. (20)

Neither has the privatisation of the banks delivered consumers better quality and cheaper services as the current Royal Commission (2018) demonstrates. Examples of problems with privatisation already exist in the Australian health system such as through the growth of private health insurance leading to increased premiums and surgical fees; in contrast, "public hospitals in NSW and Victoria are more cost efficient than their private counterparts by more than 3 per cent and 4 per cent respectively" (21)

3.2 What will happen if the Not for Profit sector is eviscerated?

A "blind belief" in privatisation may mean the loss of a valuable sector and its contributions to both Australian society and the economy before they are fully understood. Unemployment may rise and inappropriate hospitalisations may also rise. Government departments are likely to come under more financial pressure as will the NDIS, because secondary prevention, health literacy and information services have not been provided.

In the excerpt from the Parliamentary Library below, the authors considered the question of what happens to the community sector because of increased privatisation as long ago as 1998. The community sector becomes vulnerable to market failure with the consequence that 'at risk' people lose services essential to their survival and well-being (22).

A Prognosis for Community Services?
Over recent years, in spite of the government preoccupation with issues of overlap and duplication of community services, and with general reforms which have driven the need for improved accountability, the issue having the greatest impact upon the service delivery system is privatisation and the contracting-out of services. A great deal of faith is being invested in a market-driven approach to community service provision being implemented by all spheres of government, although in some places, it must be acknowledged, the approach is incremental rather than accelerated.

But what happens if the market breaks down? What might our society look like? In the money market, companies and shareholders sustain losses and the 'fit' survive. In the sector which provides for the least advantaged in society, a system breakdown will almost certainly see a gradual fraying of the somewhat patched community 'safety net'. The most vulnerable or at risk people in society will bear the brunt of market failure – we can expect to see greater incidences of acts of desperation by service recipients as people in their community support networks become stressed by increased caseloads and responsibilities, or because less-qualified or part-time staff are unable to pick up on 'cues' indicating their cries for help. We may also expect to see increased evidence of poverty traps, because there is a lack of any effective social policy overview. We may expect to see more anger and frustration, because there are fewer opportunities for people to have their say about how a service ought to be developing and catering for their needs. We may expect to see less trust and social cohesion, because there are fewer deposits being made by ordinary people and by governments in the bank of social capital.

While there is no opportunity to reverse the clock on privatisation, service organisations, providers and recipients are all calling for governments to apply specific checks and balances to ensure that the needs of service recipients are met holistically and that service recipients are not worse-off as a result of privatisation and contracting-out. The need for an inclusive coordinating social policy mechanism, in which the Commonwealth Government would take the lead role, has often been suggested. Indeed, ACOSS argues that such a mechanism is urgently required. Such a mechanism may help to ensure that confidentiality provisions do not become a barrier to social policy development. It should include government and non-government sector players, providers and recipients of services. It would need to ensure release of sufficient resources so that all stakeholders are able to participate. Although by its very nature there may never be a perfect model of community service planning and delivery, the imperative has never been greater to overcome fragmentation in service mix, scope, availability and affordability and set desired community objectives. Governments, alone, cannot achieve these tasks. Overseas experience has illustrated that to tackle issues in a piecemeal fashion, from service to service or individual to individual, has the potential of denying society's development. (22)

While this viewpoint presents a dire picture, it neglects to address that the steady growth of privatisation such as in Aged Care and the NDIS will concentrate on providing services to the highest volumes of clients. Cost efficiencies require that services are homogenised, so that aged care services are delivered as though all older people have the same requirements, all disabled people have access to the same services, despite their disabilities differing. Thin markets, the domain of many NFPs such as highly specialised services, will be neglected under privatisation:

"One of the concerns which is yet to be addressed is how we, as a community, will continue to support the needs of those individuals which require a very specialist level or type of care, those whose care requires a very high level of overhead costs, or those in remote or regional areas (meaning providers) are unlikely to reach the volumes they require to remain sustainable.

This concern is not new, and advocates in the sector have been writing on the topic since the announcement of the social sector funding shift. To date, there has been no firm resolution as to how these clients will be serviced. The National Disability Services (NDS) has advocated there is a case for block funding to remain in place for these types of clients." (23)

With growing privatisation, it is those NFPs that work in thin markets, that is, specialist conditions with small numbers, that will be most affected. Privatisation requires profitability for sustainability and this is achieved through competition and ultimately concentration of funds into the most successful competitors. "Growth and change in Australia's charities: 2014 to 2016" suggests that this is in progress (24).

Overall, the number of charities has reduced between January 2014 and December 2016. Of those who have ceased to operate, some had their charitable status revoked. Sixteen per cent of charities lost their charitable status due to merger. The report gives no details about this activity, but this activity is indicative of increasing concentration.

The larger charities grew larger in income from all sources, a move indicating increasing concentration:

"The largest 1% of charities, measured in terms of their gross income, account for more than half of all income in the sector, and this ratio has remained relatively stable over the past two years (56.3% in 2014 and 57.0% in 2016). However, this is equivalent to a $7 billion (or 11.3%) increase in the total gross income of the top 1% charities, slightly higher than the 10% increase across the sector." P.30

Some charities reduced the jurisdictions they operated in, which suggests they might be concentrating on more profitable jurisdictions, though there is no evidence in the report for this. Ten per cent of charities reported different main activities in 2016 to the main activities in 2014, suggesting responses to a market.

Additionally, the overall number of paid employees has increased; primarily, these are casual employees. At the same time, paid staff numbers fluctuated among the smaller charities, suggesting less certainty. Government grants increased but these may have been directed to hospitals, educational institutions and research facilities. Grants to environmental charities decreased while grants to animal welfare increased. Sixteen per cent of charities merged. The report gives no details about this activity, but this activity is indicative of increasing concentration.

While this data suggests concentration, it must be emphasised that it is difficult to analyse in terms of its impact on NFPs in the health sector since this includes hospitals and medical research facilities.

3.3 Waiting for paradise to be paved

Pitcher Partners suggest that rather than waiting for the funding to be reduced, there are other strategies for NFPs to consider which may allow them to continue to operate in thin markets (23).

- Cross Subsidisation: As the term suggests, this option means a NFP concentrates on the most profitable services and then uses the surplus to subsidise the less profitable more specialised services.
- Social Enterprise: Establishing a profit-making social enterprise allows for the profit to be used to support the activities of the parent organisation. This option requires a board that understands business and is fully informed of the legal and regulatory ramifications of its actions. It also requires high level strategic planning and set-up funding.
- Partnerships between NFPs: Partnering with other NFPs, or even a for-profit organisation, has the advantage of cutting back on duplicating services, sharing back-of-house services, perhaps dividing up a 'territory' for more efficient service delivery, sharing expertise or specialising in markets and services. Levels of trust must be high for this to work, especially where one NFP may dominate the other.
- Mergers: Pitcher Partners suggest that where a NFP works in thin markets, survival may depend on a merger. A partnership may be a step leading to this outcome and allows time to explore the full impact of such a move.

In many instances, NFPs that operate in thin markets delay too long before taking action. Some of this is due to distrust and competitiveness between NFPs. Competitive cultures in Australia also infect NFPs lobbying to retain their block funding from governments, as well as engaging in tendering for government services.

There is another strategy that should be considered. This is collective action. This does not have to be synonymous with collectives such as unions and strike action. After all, motorists agreeing to drive on the same side of the roads represent a form of collective action, as might be voting in a democracy. Lobbying groups such as in mining and farming are other forms of collective action.

While collective action is a feature of NFPs working in environment protection or climate change, there are few examples of collective action undertaken by NFPs in the health and disability sectors.

One example of successful collective action comes from 2011.

PRESSURE on the federal government over the cost of funding medicines has grown after its own expert panel recommended another six significant drug treatments be added to the list of prescription subsidies.

The latest batch of approved drugs joins a list of seven others recommended for inclusion on the Pharmaceutical Benefits Scheme that the Gillard cabinet has deferred for budgetary reasons.

The Gillard government has deferred a batch of drugs from being included in the Pharmaceutical Benefits Scheme, for budgetary reasons.

The new drugs to join the waiting list include new or revised treatments for colon cancer, multiple sclerosis, bipolar disorder and hypertension.

The government's decision to pit cost-saving against potential life-saving measures has drawn criticism from doctors and patient groups, who say it undermines the present evidence-based process for determining which drugs get subsidised.

Health Minister Nicola Roxon will attend a meeting in Melbourne tomorrow to face consumer, pharmaceutical and medical leaders to discuss the list and the delays.

Drugs require approval from the Pharmaceutical Benefits Advisory Committee to be included on the list and, after price negotiations, the decision of cabinet.

But critics say if the efficacy of a drug is not the sole criteria, the listing process could become politicised, with intense lobbying from drug companies which stand to make or lose hundreds of millions of dollars from a decision.

Inclusion on the PBS means subsidised drugs – which can cost thousands of dollars per treatment – are available to patients for between $5 and $34 a prescription.

Mark Metherall Sydney Morning Herald 28 April 2011

Led by Consumers' Health Forum, some 20 NFPs joined in a campaign that resulted in the Government reversing its decision. An important aspect of this collective action is that it was an activity that united a normally disparate group of NFPs. Having achieved the objective collectively did not result in a more permanent alliance. This is likely to be more attractive to some NFPs than belonging to a group where members are expected to support all or most campaigns.

We have seen above that the contribution that NFPs make to the health system, the community and the economy is poorly understood. Another part of collective action might relate to making these contributions better known. How this might be achieved requires more planning and research such as that exemplified above by Gilchrist (7). It also requires lobbying on behalf of the sector, where contributions of NFPs are articulated. Consider industry groups that both support their members with information, training and advocacy. Examples are Australian Industry Group (AI Group), the Housing Industry Association (HIA) and National Farmers' Federation (NFF). The latter is instructive. While NFPs are finding that their attempts to advocate lead to threats of loss of charitable status, the NFF claims its key role is advocacy: that is, to form productive partnerships with Parliamentarians and bureaucrats to ensure that the interests of agriculture are understood and included in policy deliberations. It undertakes this in an apolitical manner (25). This form of advocacy is not under any threat.

An aspect to be considered here is that NFPs have little to lose at the moment, except their timidity. Those NFPs with core funding have adopted a level of acquiescence to governments and their departments which has not been reflected in government budgetary responses. Successive governments have continued to cut the funding of NFPs. However, as a group NFPs

have huge political and economic leverage based on the numbers they employ and the funds many command, should they choose to exercise it.

4. RECOMMENDATIONS

NFPs represent relationships. Many of these relationships will be lost as those preferring to make a profit, or being forced to make a profit, will abandon fostering relationships that are unprofitable. The community needs to decide if it wants competition policy to swamp such relationships for the sake of competition.

- Consider collective action on single issues related to sustaining the whole NFP sector in health and disability, as a first step.
- Encourage greater utilisation of NFP services by the health, welfare and disability sectors where thin markets predominate. This entails seeking opportunities to be seen as specialist services.
- Build the sector of specialist health NFPs as a lobby group, basing this on successful models of industry groups.
- As a group
    - Build partnerships across the broader health sector to increase understanding of NFPs' contributions to health, including Health Departments, professional bodies such as AMA, RACGP, specialist colleges, private health insurers.
    - Undertake stronger promotion of the contribution NFPs make to people's well-being through engagement with journalists and social media.
    - Engage policy officers to ensure that NFPs are involved in decision-making at the state and Federal policy levels.
    - Undertake full evaluations of the contributions of NFPs which includes more than their economic value so that the community understands what will be lost. Such an evaluation should include the impost on the community in terms of their donations to support a NFP.

REFERENCES

(1) The Guardian Australian ed. Disability groups facing closure as states withdraw funding. https://www.theguardian.com/australia-news/2017/oct/13/disability-groups-facing-closure-as-states-withdraw-funding-before-ndis

(2) The Guardian Australian ed. NDIS- Children's support falling at a rapid rate due to underfunding. https://www.theguardian.com/australia-news/2017/sep/27/ndis-childrens-support-failing-at-rapid-rate-due-to-underfunding

(3) The Guardian Australian ed. Disability advocacy groups warn funding withdrawal may force them to close. https://www.theguardian.com/australia-news/2017/nov/27/disability-advocacy-groups-warn-funding-withdrawl-may-force-them-to-close

(4) The Guardian Australian ed. NDIS in crisis say disability groups as complaints soar. https://www.theguardian.com/australia-news/2017/aug/26/ndis-in-crisis-say-disability-groups-as-complaints-soar

(5) Submission from the Councils of Social Service in Australia to the National Competition Policy Review, November 2014; http://competitionpolicyreview.gov.au/final-report/

(6) Epilepsy Foundation. Submission to Department of Health and Human Services Victoria 2017 www.epilepsyfoundation.org.au (not available for public use).

(7) Gilchrist D. (2017) NDIS pricing: new research confirms risks to service users http://www.baxterlawley.com.au/ndis-pricing-new-research-confirms-risks-to-service-users/

(8) VACCHO Submission to the NDIS Independent Pricing Review October 2017 http://www.vaccho.org.au/assets/01-RESOURCES/TOPIC-AREA/POLICY/SUBMISSIONS/2017/VACCHO-Submission-into-NDIS-Independent-Pricing-Review.pdf

(9) Australian Commission for Safety and Quality in Health Care National Statement on Health Literacy: Taking Control (2014) https://www.safetyandquality.gov.au/wp-content/uploads/2014/08/Health-Literacy-National-Statement.pdf.

(10) Australian Commission for Safety and Quality in Health Care https://www.safetyandquality.gov.au/wp-content/uploads/2014/08/Health-Literacy-Taking-action-to-improve-safety-and-quality.pdf.

(11) Cimasi R, Sharamitaro A & Seiler R The Association between Health Literacy and Preventable Hospitalizations in Missouri: Implications in an Era of Reform J Health Care Finance 2013; 40(2):1–16

(12) Epilepsy Australia www.epilepsyaustralia.net/epilepsy-sudep/

(13) Epilepsy Foundation https://www.epilepsy.com/article/2013/11/sudep-need-global-conversation

(14) Boyle F, Donald M, Dean J, Conrad S, Mutch A, Mental health promotion and non-profit health organisations. Health Soc Care Community. 2007 Nov;15(6):553-60.

(15) Bowel Cancer Research Australia https://www.bowelcanceraustralia.org/bowel-cancer-research-foundation

(16) Ms Research Australia http://www.msra.org.au/

(17) Dept. of Health, Government of Australia. Seventh National HIV Strategy 2014-2017. http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-bbvs-hiv

(18) Peers for Progress http://peersforprogress.org/learn-about-peer-support/science-behind-peer-support/
(19)Sav A et al. Consumer health organisations for chronic conditions: why do some people access tem and others don't? Primary Health Care Research & Development Feb 2014 DOI: 10.1017/S1463423614000036
(20) Van Onselen L How privatisation pushed up Australia's electricity costs. Unconventional economist 28 July 2017 https://www.macrobusiness.com.au/2017/07/privatisation-pushed-australias-electricity-costs/
(21) The McKell Institute Risky business: the pitfalls and missteps of hospital privatisation November 2014. https://mckellinstitute.org.au/app/uploads/McKell-Institute-Risky-Business-Nov-2014.pdf
(22)Parliamentary Library Parliament of Australia. Will Privatisation and Contracting Out Deliver Community Services? Research paper 15 1998. https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/RP9798/98RP15#intro
(23) Pitcher Partners Thin markets in the NDIS 2016. http://www.pitcher.com.au/news/thin-markets-ndis
(24)Ramia, I, Powell, A, Cortis, N and Marjolin, A 2018, Growth and change in Australia's charities: 2014 to 2016, Centre for Social Impact and Social Policy Research Centre, UNSW Australia.
(25) National Farmers' Federation Annual Review 2016-2017 http://walshmedia.realviewtechnologies.com/?xml=National_Farmers_Federation&iid=157109#folio=2