



Response to:

**The Productivity Commission Draft Report
Disability Care and Support**

5 May 2011

Introduction:

Arthritis Australia is pleased to have the opportunity of responding to the Production Commission Draft Report – Overview and Recommendations for Disability Care and Support.

As the national, peak consumer body representing almost 4 million Australians living with arthritis – the major form of disability and pain in Australia – we welcome the underlying principles of the National Disability Reform Agenda and the intention of finding the best solutions for improving care and support services.

In this submission Arthritis Australia is commenting on some recommendations to ensure those in our constituency in most need will receive fair and equitable opportunities under the proposed National Disability Strategy. We have documented in this response, relevant commentary/recommendations from The Productivity Commission Draft Report – Overview and Recommendations coupled with Arthritis Australia's position statements.

This response has been prepared in collaboration with Arthritis Australia's Consumer Network; Consumer Representative/Arthritis Australia Board, Wendy Favorito; President, Prof Patrick McNeil; Medical Director/Arthritis Australia Board, Prof Graeme Jones; Arthritis ACT; Arthritis NSW; Arthritis Queensland; Arthritis SA; Arthritis Tasmania, Arthritis WA; and the Australian Rheumatology Association.

In principle, Arthritis Australia supports the Australian Government's commitment to developing a broader and more holistic National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers.

However, we believe that The Productivity Commission's Draft Report – Disability Care and Support does not adequately define groups and categories of people living with disabilities associated with arthritis - an umbrella term for more than 100 conditions, each with varying degrees of functional impairment and each requiring varying elements of support.

We would like to be reassured that the determinations for eligibility, or otherwise, for the National Disability Insurance Scheme (NDIS) is clearly articulated, that any decisions are subject to an appeal, and that these aspects are enshrined in legislation in order to protect the integrity of the scheme.

Severity of arthritis:

According to the Australian Institute of Health and Welfare, in 2003, an estimated:

- 592,000 Australians living with arthritis had profound disability, meaning that they were unable to do, or always needed help with, one or more core activity.
- 646,000 Australians living with arthritis had severe disability. These people sometimes needed help with a core activity.
- 699,000 Australians living with arthritis had moderate disability, meaning they did not need assistance but had difficulty performing a core activity.
- 1,057,000 Australians living with arthritis had mild disability, meaning they had no difficulty performing a core activity but used aids and equipment because of their disability. These people were unable to walk 200 metres; walk up and down stairs without a handrail, easily bend to pick up an object from the floor, use public transport and/or use public transport without help or supervision.

From this survey, an estimated 545,543 people aged 35 years or over reported arthritis to be their main disabling condition. The majority (89%) of these people experienced specific restrictions: they required assistance in various activities of daily living such as self-care and mobility. Around one in three reported schooling or employment restrictions, however, a large proportion of people were retired. More than 34% of those with specific restrictions reported profound or severe core activity restriction. The personal characteristics of people with disability associated with arthritis are quite similar to people with disability in general.

<Australian Institute of Health and Welfare / Impairments and disability associated with arthritis and osteoporosis 2007 and A Snapshot of Arthritis in Australia 2010>

The burden of musculoskeletal disorders in Australia is profound. Musculoskeletal conditions, specifically osteoarthritis (OA), rheumatoid arthritis (RA), juvenile arthritis (JA) and osteoporosis (OP), are therefore recognised as National Health Priority Areas.

Musculoskeletal conditions account for the greatest proportion of long term health conditions in Australia, other than long term eye disorders which are usually correctable.

In 2009, 6.5% of Australians reported a disability due to a musculoskeletal condition – almost 1 in 3 people (1:2.86) who reported a disability. Although mortality associated with musculoskeletal conditions is minimal relative to other chronic conditions, morbidity is significant due to the common sequelae of chronic pain and functional disability. In 2010 musculoskeletal conditions accounted for only 0.6% of years of life lost yet accounted for 7.7% of years lost to disability, collectively responsible for 4% of the national disease burden in terms of disability-adjusted life years <Australian Institute of Health and Welfare., 2010 >. Musculoskeletal conditions also impose a profound burden on human capital in Australia. For example, rheumatoid arthritis affects people during income earning years and has a significant impact on work and therefore earning capacity <Shanahan, 2008>.

Arthritis overview:

Arthritis is not a single disease. It is a word that represents a group of more than 100 conditions that primarily affect the muscles, tendons and joints of the body and, in addition, can damage every major organ. (To avoid confusion, please note that the nationally recognised number for the grouping of ‘arthritis and musculoskeletal conditions’ is 150 – also mentioned within this response.)

While nearly every joint in the body can be affected, the major functional impact of arthritis is by involvement of hands, knees, shoulders and feet. People can be affected in all sorts of different ways but the most common symptoms of arthritis are pain, joint stiffness, swelling in one or more joints, fatigue and loss of function (notably manual dexterity, strength and mobility).

Most severe forms of arthritis can cause permanent joint damage and disability. In addition to the traditional symptoms, some forms also affect tissues and organs of the body (e.g. respiratory or cardiac systems) and people with these conditions have an increased risk of cardiovascular disease, stroke and depression.

There is no cure for arthritis.

There is a misconception that arthritis is an older person’s disease. However, arthritis does not discriminate and children as young as 18 months old can be diagnosed with a form of arthritis – and 62% of people with some form of arthritis are of working age (15-64 years)(Access Economics report, Painful Realities: The Economic Impact of Arthritis in Australia in 2007).

In some cases, the disease may disappear, but in most it persists with overlying ‘flares’ that may come and go for many years. These flares can occur without warning. Those affected, never know how their mobility or functionality will be from one day to the next. Mornings are always extremely difficult for these people, their swollen and painful joints making it impossible to function, especially in performing everyday tasks such as travelling to work or taking children to school.

Unlike some disabilities that are highly visible to the general community, such as those requiring the use of a wheelchair, vision aid or hearing aid, arthritis can be invisible and, therefore, is often referred to as a ‘hidden disability’. A person struggling with arthritis may not have a visible disability but is enduring invisible symptoms such as constant pain, joint restriction, chronic fatigue and the associated functional and mobility issues.

In recognition that arthritis is a major cause of disability and pain, the Australian Government declared Arthritis and Musculoskeletal Conditions a National Health Priority in 2002. Nearly one in five Australians has arthritis (almost four million people). By 2050 it is projected there will be 7 million Australians with arthritis – 23.9% of the projected population of 29.4 million.

An Access Economics’ study, Painful Realities – The Economic Impact of Arthritis in Australia in 2007 reported that the total cost of arthritis to the Australian economy was estimated to have been \$23.9 billion and that the allocated health system expenditure associated with arthritis was \$4.2 billion. The largest component of health system cost was hospitals, which accounted for 44% of total allocated expenditure. The cost of aids or devices to assist Australians living with arthritis in carrying out their daily activities or make additions or modifications to their home was estimated at \$211 million.

The main bearers of arthritis costs in Australia are the individuals with the condition themselves who, it is estimated, shoulder 61% of the total cost – largely as a result of being the bearer of the burden of disease.

Emotionally and socially, the hidden costs of arthritis are immeasurable. Providing The Australian Government’s proposed National Disability Insurance Scheme recognises the disability and needs of Australians struggling to maintain mobility and independence – and adequately supports their desire for leading productive lives and achieving enhanced quality of life – the future will look a lot more positive for those in need.

In the Australian Institute of Health and Welfares report, Australia’s Health 2010, it was acknowledged that arthritis is responsible for significant activity limitation over time, but the type of limitation experienced varies with the type and severity of the condition. For example, people with rheumatoid arthritis are at high risk of work disability as soon as their symptoms occur. In contrast, osteoarthritis usually develops more gradually and does not tend to limit people’s activities until they are retired or close to doing so.

Response to The Productivity Commission's Draft Report – Overview and Recommendations – Disability Care and Support:

SCOPE OF THE REVIEW

The Productivity Commission is requested to undertake an inquiry into a National Disability Long-term Care and Support Scheme. The inquiry should assess the costs, cost effectiveness, benefits, and feasibility of an approach which:

- *Provides long-term essential care and support for eligible people with a severe or profound disability, on an entitlement basis and taking into account the desired outcomes for each person over a lifetime*
- *Is intended to cover people with disability not acquired as part of the natural process of ageing (pV)*

Arthritis Australia's position is:

- We would like a better definition of 'natural process of ageing'.
- Arthritis is not inevitable and the guidelines for eligibility must ensure older people with arthritis are not assessed as having their disease simply because they are older.
- There must be clear recognition of older people having arthritis as an acquired disease process.
- There must be recognition of the various forms of arthritis and their differing symptoms, affects and rates of functional loss.

As acknowledged in Australia's Health 2010 (AIHW):

'Arthritis and musculoskeletal conditions are very common in Australia and they are responsible for much pain and disability. They place significant burdens on the community, both economic and personal, through the need for hospital and primary care services, disruptions to daily life and lost productivity.'

'There are more than 150 forms of arthritis and musculoskeletal conditions, and their causes include overuse of joints, congenital anomalies, metabolic or biochemical abnormalities, infections, inflammatory conditions, trauma and cancer. These conditions result in few deaths but can cause significant pain and disability, severely limiting a person's ability to perform everyday tasks at home and work.'

Arthritis can fluctuate in severity over time and some people will, therefore, at various times not be assessed as having a severe or profound disability. There should be acknowledgement that some diseases will vary in severity and presentation over time because they are not static disease conditions. This relates to the abovementioned periods of 'flares' of disease which people with arthritis can experience. Episodic bouts of pain and immobility deserve recognition under the proposed scheme - as does the fact that ageing is only one of the key factors for osteoarthritis and not a key factor for inflammatory forms such as rheumatoid arthritis, gout, ankylosing spondylitis, psoriatic arthritis, etc.'

For the above reasons, Arthritis Australia strongly recommends The Productivity Commission reviews and re-writes the inclusion/exclusion clauses for 'arthritis and musculoskeletal conditions' to ensure greater clarity. As well, it may be useful to undertake a review of how these conditions are treated in similar schemes internationally to establish a better understanding of the terms of reference.

Includes a coordinated package of care services which could include accommodation support, aids and equipment, respite, transport and a range of community participation and day programs available for a person's lifetime (pVI)

Arthritis Australia is a member of the National Aids and Equipment Reform Alliance and continues to support their position, as mentioned in a submission to the Productivity Commission Inquiry into a Long Term Disability Care and Support Scheme:

‘Aids and equipment is a fundamental enabler for people with disabilities in all aspects of their lives, in much the same way as other disability services. It is mostly miscast as supplementary to other disability services, and is not fully recognised as a genuine service in its own right. For many people, equipment can facilitate independence and enable people to engage in the community and increase self-reliance. However, the existing disability equipment schemes for people with disabilities are underfunded and cannot meet demand. Consequently, their processes are more focused on gate-keeping and prioritisation of need than on appropriately meeting equipment needs, and are therefore not useful models for consideration by the Commissioners.

‘There is good evidence that the delivery of appropriate and timely aids and equipment to those who need it can: improve the quality of life for those with functional impairments and their families; reduce residential care admissions; reduce family carer injuries and stress; increase participation in employment and education; reduce hospital admissions; and shorten hospital stays (AIHW 2006 and 2003; Audit Commission 2004, 2002 and 2000).’

For many people living with arthritis, partial access to certain elements of the proposed National Disability Insurance Scheme may suffice. For example, access to relatively simple aids such as appropriate footwear and/or minor home modifications can make all the difference to function and will foster independent living, health and wellbeing.

Current state/territory-based aids & equipment programs are inconsistent, clumsy and often inaccessible for Australians struggling with their arthritis.

The Commission is proposing that the Australian Government take responsibility for funding the entire needs of the NDIS. To finance the NDIS, the Australian Government should direct payments from consolidated revenue into a ‘National Disability Insurance Premium Fund’, using an agreed formula entrenched in legislation. A tax levy would be a second-best option. (p3)

Arthritis Australia acknowledges the intent of overcoming the problems in the present system but remains unclear about the manner in which the NDIS will be funded. It is Arthritis Australia's position that:

- Private health insurance schemes should include packages to support the national scheme.
- Appropriate and timely outcomes and evidence-based audits should be conducted to evaluate the cost-effectiveness of the scheme.
- Current Commonwealth and State-funded agencies will have to be reviewed to establish how they may fit into the NDIS, if at all.
- Current funding for these agencies may need to be re-directed to central administration of a National Disability Insurance Scheme but that adequate consultation with stakeholders be undertaken to ensure transparency and understanding of the proposals.

Price Waterhouse Coopers' report National Disability Insurance Scheme (October 2009) reviewed examples of social insurance schemes in Germany, Singapore and New Zealand and stated:

'The German scheme provides an example of a clear recognition of the cost burden of an ageing population, and an attempt to fund and manage this burden within an insurance type context. The cost escalation in the scheme – more than doubling in 10 years, or a compound growth rate of 7% per annum, demonstrates the risks involved in an unfunded approach where a clear plan is not anticipated.

The Singaporean scheme provides one approach to dealing with a comprehensive funded social security, retirement savings and health care.

'A particularly relevant feature of the NZ Accident Compensation Corporation (ACC) scheme is that over recent years it has faced severe pressure from cost and liability escalation in their serious injury cohort. This has necessitated the reviewing of the serious injury governance and service delivery model to one which is far more focussed on outcomes and evidence-based.'

Arthritis Australia expects that learnings from the above schemes will inform the Australian Government, before implementation, about the ongoing viability, sustainability and cost-effectiveness of the proposed changes for a centrally-managed, national scheme.

TIER 3: ACCESS TO PUBLIC-FUNDED, INDIVIDUALISED SUPPORTS

The NDIS would also not cover people whose needs would be best met by other systems. Accordingly, the NDIS would not cover people: (p14)

- ***with bad backs and other musculoskeletal conditions would also typically receive assistance from the health system.***
- ***Whose needs would best be met in the aged care sector***

Arthritis Australia believes there needs to be clarity associated with the above two statements.

The description of 'bad backs and other musculoskeletal conditions' is too broad, ambiguous and contradictory. It infers that Australians living with severe disability associated with arthritis will be excluded from the NDIS and conflicts with Draft Recommendation 3.2 'significant difficulties with mobility, self-care and/or communication'. We know 'musculoskeletal conditions' are one of the most common causes of disability so fail to understand why this segment be excluded from a disability support scheme.

The NDIS should differentiate the health care system provision of acute/chronic medical care that an individual illness may require, from the functional loss and disability induced by that illness that NDIS will support. This is comparable to the acute/chronic care of injuries in the health service which will be complemented by the National Injury Insurance Scheme.

'Whose needs would best be met in the aged care sector' requires further explanation to be understood.

DRAFT RECOMMENDATION 3.2

.....meet one of the following conditions:

- *have significant difficulties with mobility, self-care and/or communication be in an early intervention group, comprising:*
 - *those for whom there was a reasonable potential for cost-effective early therapeutic interventions (as in autism and acquired brain injury)*
 - *those with newly diagnosed degenerative diseases for whom early preparation would enhance their lives (as in multiple sclerosis)*

Arthritis Australia believes that severe and inflammatory forms of arthritis must be recognised under the above categories. Scientific evidence shows that early diagnosis and proper management of arthritis, including therapeutic interventions such as biologic medications, can make a vast difference in arresting joint erosion and deformity. These forms of arthritis include but are not exclusive to juvenile idiopathic arthritis, rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis.

DRAFT RECOMMENDATION 3.3

Support should be provided outside the NDIS for people whose support needs would be more appropriately met by the health and/or palliative care systems, comprising:

- *Those who would benefit from largely medically oriented interventions (including less restrictive musculoskeletal and affective disorders, and many chronic conditions)*

Arthritis Australia accepts that diagnosis and treatment of arthritis belongs in the primary health care setting but requires further clarification of what is meant by ‘restrictive musculoskeletal disorders’. Again, it raises the need for more specific details of the conditions/illnesses which will be eligible under the proposed NDIS and the processes for deliberation and appeal.

DRAFT RECOMMENDATION 3.7

The supports to which an individual would be entitled should be determined by an independent, forward-looking assessment process, rather than people’s current service use.

Arthritis Australia strongly urges that there be provision in the scheme for conditions such as arthritis to be progressive (as opposed to being fluctuating in nature). A person may be assessed as having a mild disability at their first assessment – but should not be automatically excluded from future access to the scheme so they can request re-assessment if their disease severity worsens longer term.

DRAFT RECOMMENDATION 5.2

The assessment process should be a valuable intervention in its own right, rather than just an entry point to supports. The process should:

- *draw on multiple sources of information, including:*
 - *information provided by the individual with a disability, including their aspirations and requirements for supports*
 - *information provided by unpaid carers*
 - *current medical information on the person with a disability*
- *access the nature, frequency and intensity of an individual’s support needs. The process should be person-centred and forward looking and consider the supports that would allow a person to achieve their potential in social and economic participation, rather than only respond to what an individual cannot do*

Arthritis Australia acknowledges that there will be many Australians with arthritis who will receive support from the health system but, at some stage, their needs would be better served by a disability support system. Other patients may be very disabled but with active treatment could become more functional, while those people with arthritis in the workforce may still require assistance, support and treatment.

Therefore, there needs to be mechanisms from which consumers can benefit from disability support when it is needed and not be excluded because at one point they were assessed as not needing it. Similarly, the reverse situation applies. This is a critical issue for people living with an unpredictable condition such as arthritis.

DRAFT RECOMMENDATION 5.5

The NDIS should periodically reassess people's need for funded support, with a focus on key transition points in their lives.

Arthritis Australia reminds the reader that the impact of arthritis can vary depending on the activity/life participation role the person is undertaking. For example, their arthritis may not be a problem while studying but may become problematic upon trying to enter the workforce. This aspect of eligibility should be guaranteed through legislation.

DRAFT RECOMMENDATION 7.3

The Australian Government, together with state and territory governments, should establish an advisory council. The council should provide the board of the NDIA with ongoing advice on its activities and effectiveness in meeting its objectives, from the perspectives of people with disabilities, carers, suppliers of equipment and services and state and territory service providers and administrators.

- ***The council should comprise representatives of each of these groups.***

Arthritis Australia believes that there must be adequate consumer representation on the board and advisory councils associated with the governance of the National Disability Insurance Agency. In particular, their responsibilities be defined by legislation and that advisory councils have direct input into policy direction, along with the administrators and other expert input.

DRAFT RECOMMENDATIONS 12.1 / 12.2

Where should the money come from?

Refer abovementioned comments on page 5.

DRAFT RECOMMENDATION 13.4

The Australian Government should amend s.65(1) of the Fair Work Act 2009 to permit parents to request flexible leave from their employer if their child is over 18 years old, but subject to an NDIS assessment indicating that parents are providing a sufficiently high level of care.

After monitoring the impacts of this legislative change, the Australian Government should assess whether it should make further changes to the Act to include employees caring for people other than children.

Arthritis Australia supports this recommendation. Carers are an integral part of Australia's health system and should be able to access additional support as outlined in this recommendation. According to Carers Australia, as well as impacts on their own health, caring has a negative impact on their employment and education prospects, their financial position, and their ability to participate in social and community life.

Summary:

Arthritis (an umbrella term covering more than 100 conditions) is associated with significant disability in people aged 35 years or over. Disability is more commonly reported by females than males. The majority experience specific restrictions, requiring assistance with various activities of daily living such as self-care and mobility. A small number of people with disability associated with arthritis report employment restrictions. More than 30% of people with disability associated with arthritis have a profound or severe core activity limitation. Those people were unable to do, or always require assistance with, one or more core activity.

Of major concern is recognition of the progressive nature of arthritis overlaid with flares of disease causing episodic functional decline. The ABS 1998 Survey of Disability, Ageing and Carers defined disability as 'any person with a limitation, restriction or impairment which has lasted, or is likely to last, for at least six months and restricts everyday activities'.

Arthritis Australia calls for further recognition of episodic disabilities, defined as 'a physical or mental illness that is unpredictably recurrent and impacts on personal ability to actively engage in the social and employment environments'. These bursts of disability can occur for less than six months but still have a major impact on a person's ability to function. Examples of episodic disabilities include arthritis, multiple sclerosis, HIV, lupus, hepatitis C, cancer and mental illnesses.

Early intervention and support for people in the abovementioned categories will enable them to stabilise and, in some cases, improve their condition so that they can maintain a level of function within the community. A National Disability Insurance Scheme which takes this into account and has the potential to offer customised, opt-in/opt-out and/or partial care will be a tremendous boost for the quality of life for those living with a disability.

We look forward to clarification of, and would be pleased to take part in any discussion regarding, the points we have raised.

Arthritis Australia

Arthritis Australia is the peak arthritis organisation in Australia and is supported by Affiliate offices in every state and territory.

Arthritis Australia provides support and information to people with arthritis as well as their families and friends. The organisation promotes awareness of the challenges facing people with arthritis across the community, and to leaders in business, industry, and government. In addition, Arthritis Australia funds research into potential causes and possible cures as well as better ways to live with arthritis.

Arthritis Australia also acknowledges the response to The Productivity Commission from Consumers Health Forum Australia, of which we are a member.

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