

Submission: Eligibility and Reasonable and Necessary Support under the National Disability Insurance Scheme

Background

About Arthritis Australia

Arthritis Australia is the peak national arthritis organisation in Australia and is affiliated with arthritis organisations in every state and territory.

Arthritis Australia provides support and information to people with arthritis as well as their family and friends. It promotes awareness of the challenges facing people with arthritis across the community, and advocates on behalf of consumers to leaders in business, industry and government.

In addition, Arthritis Australia funds research into potential causes and possible cures for arthritis as well as better ways to live with the disease.

Arthritis in Australia

Arthritis is often referred to as a single disease but is an umbrella term for more than 100 medical conditions that affect the musculoskeletal system, specifically the joints.

Arthritis affects over 3.1 million Australians and is the most prevalent National Health Priority condition.¹ By 2050 it is projected there will be 7 million Australians with arthritis, taking into account our aging population and the impact of increasing levels of obesity.²

Arthritis and musculoskeletal conditions cost at least \$9 billion annually through the health,³ welfare⁴ and residential aged care systems.⁵ The total economic cost of arthritis, including productivity losses and lost wellbeing, was estimated at \$24 billion in 2007.⁵

Arthritis and disability

Arthritis and musculoskeletal conditions are the leading causes by far of disability and chronic pain in Australia, accounting for 30.4% of all people with disability. Nearly 600,000 people have arthritis as their main disabling condition, 14.8% of all people who report a disability. Of these, more than one in four (162,100 people) experience severe or profound core activity limitations.⁶

Nearly one in three people receiving the disability support pension does so as a result of their musculoskeletal condition at an estimated cost to government of nearly \$4 billion in 2011-12.⁴

There is a misconception that arthritis is an older person's disease but people of all ages are affected, with 62% of people with arthritis of working age (15-64 years).⁵ Arthritis is the major contributor to the annual loss in workforce participation in Australia, accounting for 40% of the total loss in fulltime employment due to chronic disease, 42% of the loss in participation in part-time employment and 24% of the total loss due to absenteeism.⁷

People with arthritis can be affected in many different ways but the most common symptoms are pain, joint stiffness, swelling in one or more joints, fatigue and loss of function (notably manual dexterity, strength and mobility). 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.

Different types of arthritis can have varying degrees of functional impairment and impairment may be chronic and progressive or episodic, with ‘flares’ that come and go without warning. Most severe forms of arthritis can cause permanent joint damage and disability.

Arthritis is often referred to as a ‘hidden disability’. A person struggling with arthritis may not have a visible disability but can endure constant pain, joint restriction, chronic fatigue and associated functional and mobility issues.

There is no cure for arthritis.

Comments on consultation paper

Arthritis Australia welcomes the opportunity to provide feedback on the proposed approach to eligibility and reasonable and necessary support to be adopted under the National Disability Insurance Scheme (NDIS). Our primary concern is to ensure that the disability support needs of people who experience severe and profound core activity limitations as a result of their arthritis are met under the NDIS.

Eligibility

Arthritis Australia generally supports the draft eligibility statement outlined in the consultation document and the approach of defining eligibility for the NDIS in terms of functional impairment and level of need, rather than by specific conditions.

We note however that how the scheme is administered, including assessment processes and guidelines, will be instrumental in ensuring that the general principles outlined in the eligibility statement are realised in practice. Stakeholder consultation on these processes will be essential in developing and implementing an effective NDIS.

Episodic conditions

Arthritis Australia strongly supports the recognition in the NDIS eligibility statement of impairments of a chronic, episodic nature. The consultation document specifically recognises episodic psychiatric disability, but other conditions, including arthritis, can also cause severe episodic disability and should be recognised.

Arthritis is not a static condition. While generally progressive in nature it is often overlaid with flares of disease which cause unpredictable, episodic bouts of severe pain and immobility and functional decline. These bursts of disability may last for less than six months at a time but still have a major impact on a person’s ability to function, requiring ongoing and long term episodic support. By providing timely access to appropriate disability support services as and when required the NDIS can assist people experiencing a disease flare to retain their independence and capacity to participate in education, the workforce and the community.

Careful consideration needs to be given to how the NDIS will meet the support needs of people with chronic episodic conditions such as arthritis and mental health conditions which require different levels of support at different times, as service providers are often poorly equipped to provide supports at short notice.

Careful consideration will also need to be given to assessment processes and guidelines adopted under the scheme to ensure that people affected by chronic episodic conditions are able to access the scheme easily and quickly when they need support.

Interface with other systems

The eligibility statement includes the requirement that “support needs will persist for the foreseeable future and are not more appropriately met by other systems including education, health and/or palliative care”.

We are concerned about how this requirement might be applied to people with arthritis whose needs often cut across the health, aged care and disability systems.

In the past for example some people with arthritis have been denied access to disability services because their condition has been considered a medical condition and not a disability, despite the associated activity limitations. While the clinical needs of people with disabling conditions such as arthritis are best met by the health system, their non-clinical needs, such as aids and equipment, transport assistance and other disability support services will more appropriately be met by the NDIS.

Other systems such as the education or aged care system may not be able to offer appropriate disability support, or may have different eligibility criteria, or may be subject to the vagaries of government budget processes. This raises the prospect of inequitable access to disability support services depending on which system is designated as the most appropriate to meet an individual’s needs. These divisions also create the potential for people with genuine needs to fall between the gaps.

A related issue is the restriction of the NDIS to people under the age of 65 years on entry. People with disability acquired over the age of 65 may require services that are more appropriately provided by the NDIS than the aged care system and there should be scope for these people to have their needs met by the NDIS. Essentially, services need to be tailored to what best meets a person’s needs rather than their age, especially where needs cannot be met by existing or traditional aged care services or facilities.

Greater clarity is required around the basis for determining whether an individual’s needs are more appropriately met by the NDIS or by other systems.

Arthritis and aging

We seek recognition within the NDIS that arthritis is an acquired disease process and not an inevitable consequence of “natural aging”. 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. Eligibility criteria must ensure that older people with arthritis are not assessed as having their disease simply because of their age.

Reasonable and Necessary Support

Arthritis Australia recognises that the sustainability and effectiveness of the NDIS will depend on limiting supports to what is considered reasonable and necessary. We generally agree with the statement of reasonable and necessary supports provided in the consultation document but would like to note the following:

- While supports provided should be effective and evidence informed it is important to recognise that the existing evidence base for disability support is poor (as identified by

the Productivity Commission) and that ongoing research will be required to build the evidence base.

- In considering what is realistic to expect from carers, individual circumstances need to be taken into account, including the level of support required to assist the person with disability in their activities of daily living and the age and health of the carer. Often people with arthritis-related disability are cared for by spouses who may be ageing or becoming frail themselves and hence are limited in the care they are able to provide. The carers may also require support themselves.
- We consider that reasonable and necessary supports should encompass:
 - Aids and equipment. In assessing aids and equipment for value for money, the NDIS needs to recognise the need to prevent further disability in both people with disability and their carers: the lightest and most appropriate aids and equipment to prevent further disability are also often the most expensive
 - Home modifications which facilitate activities of daily living and maximise independence for people with disability
 - Transport. The ability to access appropriate transport is essential to support people with disabilities to participate in education, employment and the community. Transport costs (especially taxis) can present a major barrier to social inclusion for people with disabilities
 - Assistance with child care for people with episodic conditions such as rheumatoid arthritis who have young children.

Carers

We note that the current consultation document does not address the issue of eligibility and reasonable and necessary support for carers, although the Productivity Commission did recommend the NDIS should assess carer needs as well as those of people with disabilities. We consider that eligibility and supports for carers should be clarified as soon as possible.

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¹ Australian Bureau of Statistics 2010. *National Health Survey: Summary of Results, 2007-08*

² Access Economics 2007. *Painful realities: The economic impact of arthritis in Australia in 2007*

³ AIHW 2010. *Health system expenditure on disease and injury in Australia, 2004-05..* Cat. No. HSE 87. Canberra: AIHW

⁴ Department of Families, Housing, Community Services and Indigenous Affairs 2011. *Characteristics of Disability Support Pension Recipients. June 2011 and Treasury estimates for DSP expenditure for 2011-12*

⁵ Access Economics 2007. *Painful Realities: The economic impact of arthritis in Australia in 2007*

⁶ Australian Bureau of Statistics 2012. *2009 Disability, Ageing and Carers, Australia 2009: Profiles of Disability*

⁷ Australian Institute of Health and Welfare 2009. *Chronic disease and participation in work.* Cat. No. PHE 109. Canberra: AIHW.