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Submission to the Senate Community Affairs Inquiry into The National Disability Insurance Scheme Bill 2012

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.

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Key Points

Arthritis and disability

- Arthritis and musculoskeletal conditions are by far the leading causes of disability, including severe and profound disability, in Australia.¹
- Nearly one in three people with a disability has a musculoskeletal disorder as their main disabling condition,² or receives the Disability Support Pension for these conditions.³
- There are over 100 different types of arthritis, many of which can be severely disabling, although there may be no visible impairment. Impairment may be chronic and progressive or episodic, with ‘flares’ that come and go without warning.

National Disability Insurance Scheme Bill

- We fully support the establishment of a National Disability Insurance Scheme (NDIS) in Australia and welcome the objectives and principles of the scheme as outlined in the draft *National Disability Insurance Scheme Bill 2012* (the Bill).
- The Bill establishes only the broad framework for the NDIS and does not specify key operational aspects of the scheme, such as how eligibility will be determined and what supports can be provided. These are crucial issues that will determine the effectiveness of the NDIS in achieving its objectives. The NDIS Rules which will specify these details must be developed in consultation with the disability sector and be subject to public consultation to ensure people with certain types of disabilities, such as those caused by arthritis, are not inadvertently disadvantaged as the scheme is further developed. We look forward to participating in these consultations.
- NDIS eligibility criteria and assessment processes must accommodate the needs of participants who are severely disabled due to arthritis and musculoskeletal conditions, recognising that:
 - There may be no visible impairment, but a person with arthritis may endure constant pain, joint restriction, chronic fatigue and associated functional and mobility issues.
 - Associated disability may be episodic, varying in intensity and the level of support required from time to time. Recognition of the varied supports required must be incorporated into participant plans without the need for the plan to be reviewed (as per clause 48) every time a participant experiences a disease flare.
- Clauses 24 and 25 of the Bill should be amended to clarify that impairments due to chronic pain and fatigue, which are common in many inflammatory forms of arthritis, fit within the disability requirements and early intervention requirements.
- 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, such as the health, education or aged care systems.
- Arthritis Australia should be consulted as a key stakeholder in the development of eligibility and assessment criteria and processes to be drafted under the NDIS Rules.
- Proposed arrangements whereby people with disability may be directed to seek compensation from other sources before receiving support under the NDIS are inequitable and onerous, given the financial cost, uncertain outcome and lengthy delays associated with litigation. These requirements should be removed.

Introduction

Arthritis Australia fully supports the introduction of the National Disability Insurance Scheme (NDIS) and welcomes the opportunity to provide comment on the draft *National Disability Insurance Scheme Bill 2012* (the Bill).

As arthritis is one of the leading causes of disability in Australia, our primary concern is to ensure that the disability support needs of people who experience significant core activity limitations as a result of their arthritis are met under the NDIS.

Background

Arthritis in Australia

Arthritis comprises over 100 conditions affecting the musculoskeletal system, specifically joints, and affects over 3.3 million Australians.⁴ People of all ages are affected, with 62% of people with arthritis of working age (15-64 years).⁵

By 2050, it is expected that 7 million Australians will have arthritis due to the impact of population ageing and the increasing prevalence of obesity.⁶

Arthritis and musculoskeletal conditions cost over \$9bn annually in direct costs to the health (\$4bn),⁷ welfare (\$4bn),⁸ and residential aged care (\$1bn) systems.⁹ The estimated economic cost of arthritis alone (including lost productivity and wellbeing) was \$24bn in 2007.⁹

Arthritis is a leading cause of lost productivity in Australia, accounting for 40% of the total loss in fulltime employment due to chronic disease, 42% of the loss in part-time employment and 24% of the total loss due to absenteeism.¹⁰

Arthritis and disability

Arthritis and musculoskeletal conditions are the leading causes *by far* of disability in Australia, accounting for nearly one in three people with a disability¹¹ or receiving the Disability Support Pension.¹²

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.¹³

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).

Different types of arthritis can cause varying degrees of functional impairment. 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 may endure constant pain, joint restriction, chronic fatigue and associated functional and mobility issues. This can increase the risk of mental disorders such as depression and anxiety, which occur in one in four people with a musculoskeletal condition.¹⁴

There is no cure for arthritis.

Comments on the NDIS Bill 2012

Arthritis Australia supports the principles and objects outlined in the Bill for the operation of the NDIS.

Our major concern is that the legislation establishes only the broad framework for the NDIS and does not specify key operational aspects of the scheme, such as how eligibility will be determined and what supports will be funded. These are crucial issues that will determine both the overall effectiveness of the NDIS in achieving its objectives and whether the support needs of people with a disability due to arthritis will be met under the scheme.

The Bill allows for key operational aspects of the NDIS to be set out in the yet to be drafted NDIS Rules. Because they are crucial to the effective and equitable operation of the NDIS, these Rules must be developed in consultation with the disability sector and be subject to public consultation to ensure people with certain types of disabilities, such as those due to arthritis, are not inadvertently disadvantaged as the scheme is further developed. We look forward to participating in these consultations.

Eligibility

Mostly, the disability requirements outlined in clause 24 of the Bill appear to cover arthritis associated disability, especially where there is a physical impairment affecting mobility and self-care. However, it is less clear whether impairment due to chronic pain and fatigue, which are common in many inflammatory forms of arthritis, fit within these disability requirements.

For example modern treatments for rheumatoid arthritis and juvenile arthritis can significantly alter disease progression and reduce joint damage associated with the disease, minimising physical disfigurement. However, people with these conditions can still suffer debilitating chronic or episodic pain and fatigue. This pain and fatigue may significantly interfere with their daily life but may not specifically limit their ability to undertake the activities listed in clause 24 (1) (c), namely, communication, social interaction, learning, mobility, self-care and self-management. This could potentially exclude people with these conditions from eligibility for the NDIS. Similar issues around eligibility have been reported by people with inflammatory forms of arthritis applying for the Disability Support Pension.

It is also not clear whether children with juvenile arthritis, would meet the early intervention requirements under clause 25, given that effective early treatment and support may stave off long term disability.

Consequently we recommend that clauses 24 and 25 be amended to more clearly accommodate impairment due to pain and fatigue. This could be done, for example by adding "other activities of daily living" to the list of activities in clause 24 (1) (c) and clause 25. Alternatively an additional subsection could be inserted into each clause to specify that pain and fatigue are within the definition.

These issues will also need to be addressed in the development of the NDIS Rules.

Episodic conditions

Arthritis Australia strongly supports clause 24(2) in the Bill which recognises that impairments may be chronic or episodic in nature.

Arthritis is not a static condition. While generally progressive in nature it is often overlaid with flares of disease activity which cause unpredictable, episodic bouts of severe pain and immobility and functional decline, interspersed with periods of reduced disability or disease remission. 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 support 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. A participant may need two levels of support – one for when the disease is active and one when it is less so. If their condition goes into full remission, where no assistance is required for a period of time this should not lead to cancellation of their plan and entitlements.

We recommend that recognition of the varying levels of supports that are required for episodic conditions are incorporated into participant plans without the need for the plan to be reviewed (as per clause 48) every time a participant experiences a disease flare.

People with disability who do not qualify for funded supports

The experience of many people with arthritis-associated disability is that they have difficulty in gaining access to disability services because their impairment (especially pain and fatigue) is not recognised or is considered part of "natural aging". We would be very concerned if people with arthritis were excluded from funding for disability services under the NDIS on this basis. Hence we ask that Arthritis Australia be consulted in the development of eligibility and assessment criteria and processes to be drafted under the NDIS Rules.

Interface with other systems

Clause 34 (f) of the Bill specifies that the CEO of the NDIS Launch Transition Agency needs to consider whether the required supports should be provided through the NDIS or are more appropriately provided through other mainstream services.

We are concerned about how this requirement might be applied to people with arthritis whose needs often cut across the health, education, 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, including children with juvenile arthritis, to fall between the gaps.

A related issue is the restriction of the NDIS to people under the age of 65 years on entry (clause 22). 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.

Reasonable and necessary supports

Arthritis Australia recognises that the sustainability and effectiveness of the NDIS will depend on limiting funded supports to what is considered reasonable and necessary. Clause 34 of the Bill only outlines general principles underlying the provision of support, while the methods for assessing or deciding what supports will be funded or provided under the NDIS will be set out in the NDIS Rules. As previously recommended the development of the NDIS Rules must be subject to extensive stakeholder consultation.

The development of the NDIS Rules should have regard to 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 is 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.
- Where a person with episodic disability has carer responsibilities for others, such as children or elderly parents, adequate supports such as child care or respite care should be included in necessary and reasonable supports.
- 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.
 - Occupational therapy and workplace modifications to facilitate employment participation.

- Transport and parking assistance. The ability to access appropriate transport is essential to support people with disabilities, including those with arthritis, to participate in education, employment and the community. Transport costs (especially taxis) can present a major barrier to social inclusion for people with disabilities. Access to disability parking close to workplaces and amenities is also essential to support employment and independence.

We note that the provision of supports is dependent on the supports meeting all the criteria specified in clause 34 of the Bill. This may be unnecessarily restrictive. An effective support may meet most but not all of the criteria specified: for example innovative disability supports are likely to be disadvantaged under clause 34 (d) which requires that the support is effective and beneficial for the participant, having regard to current good practice. A more flexible approach should be considered.

Compensation payments

Clause 104 specifies that the CEO of the NDIS Launch Transition Agency may require people with disability who may be entitled to compensation payments from other sources to seek that compensation before they can receive supports under the NDIS. This requirement is inequitable and onerous, given the financial cost, uncertain outcome and lengthy delays associated with litigation, and should be removed.

¹ Australian Bureau of Statistics 2012. 2009 Disability, Ageing and Carers, Australia 2009: Profiles of Disability

² Australian Bureau of Statistics 2012. 2009 Disability, Ageing and Carers, Australia 2009: Profiles of Disability

³ 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

⁴ Australian Bureau of Statistics 2012. Australian Health Survey 2011-13: First Results

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

⁶ Access Economics 2007. *Painful Realities: The economic impact of arthritis in Australia in 2007*

⁷ AIHW 2010. *Health system expenditure on disease and injury in Australia, 2004-05..* Cat. No. HSE 87. Canberra: AIHW

⁸ 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

⁹ Access Economics 2007. *Painful Realities: The economic impact of arthritis in Australia in 2007*

¹⁰ Australian Institute of Health and Welfare 2009. Chronic disease and participation in work. Cat. No. PHE 109. Canberra: AIHW.

¹¹ Australian Bureau of Statistics 2012. 2009 Disability, Ageing and Carers, Australia 2009: Profiles of Disability

¹² Department of Families, Housing, Community Services and Indigenous Affairs 2011. Characteristics of Disability Support Pension Recipients. June 2011

¹³ Australian Bureau of Statistics 2012. 2009 Disability, Ageing and Carers, Australia 2009: Profiles of Disability

¹⁴ Australian Institute of Health and Welfare 2010. When musculoskeletal conditions and mental disorders occur together. Cat. no. AUS 129. Canberra: AIHW.