

Senate Community Affairs Committee
ANSWERS TO ESTIMATES QUESTIONS ON NOTICE
Social Services Portfolio
2014-15 Budget Estimates Hearings

Outcome Number: 5

Question No: 506

Topic: NDIA

Hansard Page: CA46

Senator Siewert asked:

How long was the consultation period on the drafts? Can you provide a list of people who you are consulting with on the eight most prevalent conditions broadly with acknowledged experts, providers and representative bodies?

Answer:

In January 2014 the National Disability Insurance Agency (NDIA) published amended Operational Guidelines giving further guidance on the access criteria that must be satisfied for a person to become a participant in the National Disability Insurance Scheme (NDIS).

The amended Operational Guidelines included expanded lists of conditions that result in impairments which the Chief Executive Officer (CEO) of the NDIA considers are likely to meet certain elements of the disability requirements or early intervention requirements which form part of the access criteria. In particular, the expanded lists identify conditions that result in impairment which:

- are, or are likely to be, permanent
- result in substantially reduced functional capacity
- are likely to meet the early intervention requirements.

The expanded lists published in the amended Operational Guidelines are not determinative of eligibility for the NDIS. The lists simply identify matters to which a delegate of the CEO may have regard in determining whether a person meets the disability requirements or early intervention requirements. Nor are the expanded lists exhaustive. A person who has a condition that is not included in the expanded lists will become a participant in the NDIS if the person meets the access criteria.

The purpose of the expanded lists is to reduce the amount of unnecessary or repeated assessment required to determine whether a prospective participant meets the access criteria, where the prospective participant's impairment results from a condition that is likely to meet the access criteria.

The expanded lists were developed having regard to:

- World Health Organisation's International Classification of Diseases, Tenth revision (WHO ICD-10), which is a contemporary, internationally recognised, standard diagnostic tool used by Australia and other WHO member states for epidemiology, health management and clinical purposes. The terminology and condition nomenclature is therefore commonly used by clinicians providing medical records, diagnostic reports and clinical information likely to be considered in the NDIS access request process.

Senate Community Affairs Committee
ANSWERS TO ESTIMATES QUESTIONS ON NOTICE
Social Services Portfolio
2014-15 Budget Estimates Hearings

- Various publicly accessible medical research sources and references were used to determine the conditions which consistently meet the requirements relating to substantially reduced functional capacity and/or permanence. These references included:
 - U.S. National Library of Medicine, Genetics Home Reference – Your Guide to Understanding Genetic Conditions, <http://ghr.nlm.nih.gov>
 - U.S. Department of Health and Human Services, National Endocrine and Metabolic Diseases Information Service (NEMDIS), <http://endocrine.niddk.nih.gov/index.aspx>
 - the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM version IV and the recently released version DSM-5) - sourced in respect of conditions such as Autism Spectrum Disorder and psychiatric conditions
 - numerous other research and information sources specific to particular conditions or types of conditions.
- Existing Australian Government lists of manifestly disabling conditions, for example, the List of Recognised Disabilities used for Carer Payment (Child) and Carer Allowance (Child) purposes were also referred to, particularly for the NDIS List C of conditions for early intervention access for children under the age of 6 years. The DCLA List of Recognised Disabilities (Schedule 3, Disability Care Load Assessment (Child) Determination 2010) was developed to identify conditions consistently resulting in severe disability in children, has been refined over several years and undergone national consultations and research by panels of experts.

The expanded lists were not released as drafts for consultation prior to publication on the NDIS website. The Operational Guidelines are intended to be dynamic documents that will be updated regularly. It is expected that they will continue to be modified over time as they are informed by operational experience including feedback from participants and other stakeholders.

The NDIA continues to work with expert groups to establish severity indicators for each of the following conditions:

- Autism
- Intellectual disability
- Cerebral palsy
- Multiple sclerosis
- Stroke
- Hearing impairment
- Vision impairment.

Initially there were ten conditions but consultation with experts in intellectual disability, down syndrome, developmental delay and global developmental delay resulted in the consolidation of these conditions into one group for intellectual disability.

Following is a list of the experts groups which includes multidisciplinary organisations with research, advocacy, provider and disciplinary arms.

Senate Community Affairs Committee
ANSWERS TO ESTIMATES QUESTIONS ON NOTICE
Social Services Portfolio
2014-15 Budget Estimates Hearings

Autism

Vicki Gibbs, researcher ASPECT Clinical Psychologist/Manager – Diagnostic

Elizabeth Watson, Clinical Coordinator, ASPECT

Dr Jacqueline Small, Senior Staff Specialist, Disability Specialist Unit, Children's Hospital Westmead

Prof Katrina Williams, Paediatrician & Public Health Physician, Director, Department of Developmental Medicine APEX Australia Chair of Developmental Medicine, University of Melbourne Honorary Research Fellow, Murdoch Childrens Research Institute

A/Prof Natalie Silove | Consultant Paediatrician, Clinical Director Medical - Community, Ambulatory, Rehabilitation, Population & Allied Health (CARPA) | Head of Child Development Unit, Senior Clinical Lecturer University of Sydney

Intellectual disability

Jim Simpson, NSW Council for Intellectual Disability

Aine Healy, CEO, NSW Council for Intellectual Disability

Dr Natalie Silove, A/Prof Natalie Silove | Consultant Paediatrician, Clinical Director Medical - Community, Ambulatory, Rehabilitation, Population & Allied Health (CARPA) | Head of Child Development Unit, Senior Clinical Lecturer University of Sydney

Dr David Dosseter, Senior Staff Specialist, Director for Mental Health SCHN Clinical Associate Professor, University of Sydney

Dr Eric Emerson, Emeritus Professor of Disability & Health Research, Centre for Disability Research, Lancaster University, UK

Keith McVilly, A/Professor, Deakin University and Convenor of intellectual disability special interest group in the Australian Psychological Society

Prof Roger Stancliffe, Professor of Intellectual Disability, Centre for Disability Research and Policy, University of Sydney

Catherine McAlpine, CEO Down Syndrome Australia

TraceyLee Arestides, Executive Director, Down Syndrome NSW

A/Prof Vivian Roberts, Centre for Disability Studies, University of Sydney

Sam Arnold, Research Fellow, Centre for Disability Studies, University of Sydney

Paul Cain, National Council for Intellectual Disability, Western Australia

Senate Community Affairs Committee
ANSWERS TO ESTIMATES QUESTIONS ON NOTICE
Social Services Portfolio
2014-15 Budget Estimates Hearings

Cerebral Palsy

A/Professor Iona Novak PhD, Head of Research, Research Institute Cerebral Palsy Alliance
School of Medicine, University of Notre Dame

Jo Ford, Divisional Manager Lifepoints and Technology Services, Cerebral Palsy Alliance

Dr Natalie Silove, A/Prof Natalie Silove | Consultant Paediatrician, Clinical Director Medical
- Community, Ambulatory, Rehabilitation, Population & Allied Health (CARPA) | Head of
Child Development Unit, Senior Clinical Lecturer University of Sydney

Dr Jacqueline Small, Senior Staff Specialist, Disability Specialist Unit, Children's Hospital
Westmead

NB. A/Prof Novak coordinated feedback from a number of researchers from the Cerebral
Palsy Alliance including;

Hayley Simthers-Sheedy, Research Officer Shona Goldsmith, Research Associate Dr Sarah
McIntyre, Research Fellow Elise Stumbles, General Manager Organisational Development
Liz Foy, General Manager Client Services

Multiple sclerosis

Dr Elizabeth McDonald, Medical Director MS Society

Ms Robyn Hunter CEO MS Society

Dr Michael Pollock, Rehabilitation Medicine, Chairman, Hunter Stroke Service, Hunter
Health

Stroke

Kelvin Hill, National Manager Clinical Programs, National Stroke Foundation

Dr Michael Pollock, Rehabilitation Medicine, Chairman, Hunter Stroke Service, Hunter
Health

Mark Longworth, Manager, Statewide Stroke Services | Agency for Clinical Innovation

John Worthington, Chair of ACI Stroke Network (Stroke Services NSW) Conjoint Associate
Professor, Faculty of Medicine, University of NSW Senior Staff Specialist, Liverpool
Hospital, South Western Sydney LHD

NB. Mark Longworth liaised with all members (90+) of the Stroke Network of the Agency
for Clinical Innovation who provided feedback a collective group through him

Senate Community Affairs Committee
ANSWERS TO ESTIMATES QUESTIONS ON NOTICE
Social Services Portfolio
2014-15 Budget Estimates Hearings

Hearing impairment

Suzannah Macready, Senior Policy Advisor, The Deaf Society of NSW

Colin Allen, Community Engagement Senior Advisor, The Deaf Society of NSW

Andrew Wiltshire, Manager of Consumer and Community Services, The Deaf Society of NSW

Sara Duncan, Business Analyst, Better Hearing Australia

Sharon Plunkett, Business Analyst, Better Hearing Australia

Carla Anderson - Manager deafblind services at Able Australia

Vision Impairment

Sue Silveria, JAFF Research Fellow, RIBDC Renwick Centre, Royal Institute of Deaf and Blind Children

Julie Hegarty, CEO, Macular Disease Foundation

Rob Cummins, Research and Policy Manager, Macular Disease Foundation

Graeme Craig, Director – National Disability Insurance Scheme, Vision Australia

Andrea Lockwood, Service Innovation Project Leader, Vision Australia

Niky Hepi, Service and Team Development Leader, Vision Australia

Frances Tinsley, Executive Manager of Client Services, Guide Dogs Australia

Marion Rivers, Orthoptist, Low Vision Consultant