

The health of people with intellectual disability

Open letter to all parties contesting the federal election 2022

We applaud the development of the National Roadmap for Improving the Health of People with Intellectual Disability which was released by Health Minister Greg Hunt in August 2021. We also applaud initial actions taken towards implementation of the Roadmap.

The Roadmap provides a detailed plan for addressing the stark health inequalities that people with intellectual disability face. In recent years, evidence of these inequalities has continued to grow, including findings that people with intellectual disability die up to 27 years earlier than other people and are at least twice as likely to die from potentially avoidable causes. They are less likely to receive preventative health care and four times more likely to be hospitalised.

After a two week hearing in 2020, the Disability Royal Commission found that “people with cognitive disability have been and continue to be subject to systemic neglect in the Australian health system”.

We must urgently address the stark and sometimes deadly health inequalities faced by people with intellectual disabilities.

What is needed now is concerted action to implement the National Roadmap in accordance with its ten year timeframe including the scheduled completion of a large amount of work within the first three years.

An essential element of action is the earliest possible funding of a National Centre of Excellence in Intellectual Disability Health.

This Centre is a vital driver of action on the Roadmap including by leading research and development of best practice and being a hub of health information and training resources for people with intellectual disability, their supporters and health professionals.

We call on all parties to join the Government's commitment to the National Roadmap.

We call on all parties to commit to fund the National Centre of Excellence in Intellectual Disability Health within the next 12 months.

As campaigners with intellectual disability have said many times, "Our health counts. Can we count on you?"

Yours sincerely,

Dylan Alcott AO
Australian of the Year 2022

Robyn Kruk AO
Former Director-General, NSW Health and Premier's Department
Former CEO, National Mental Health Commission

Adjunct Professor John Walsh AO

Associate Commissioner on the Productivity Commission Inquiry into
Disability Care and Support

Jane Halton AO PSM

Former Secretary, Australian Government Departments of Health and
Finance

Shu Hua Chan

Former Chairperson, Council for Intellectual Disability

Keynote Speaker, Our Health Counts Campaign

Member, Roadmap Implementation Governance Group

Judy Huett

Speak Out Tasmania

Member, Roadmap Implementation Governance Group

Former member, NDIS Independent Advisory Council

Professor Fiona Stanley AC

Founding Director, Telethon Kids Institute

Australian of the Year 2003

Dr Karen Price

President, Royal Australian College of General Practitioners

Associate Professor Vinay Lakra

President, Royal Australian and New Zealand College of Psychiatrists

Dr Jenny Proimos

President, Academy of Child and Adolescent Health

Claire Hewat

CEO, Allied Health Professionals Australia

Kim Oates AO

Emeritus Professor of Child and Adolescent Health, University of Sydney

Former CEO, Children's Hospital at Westmead

Helen Christensen AO

Scientia Professor of Mental Health, UNSW

Professor Malcolm Hopwood

Former President RANZCP

President of the Asian Federation of Psychiatric Associations

Eric Emerson

Emeritus Professor of Disability and Health Research, Lancaster

University

Honorary Professor, Flinders University and University of Sydney

Ian Webster AO

Emeritus Professor of Public Health and Community Medicine, UNSW

Liz Marles

Former President, Royal Australian College of General Practitioners

Maria Tomasic
Former President RANZCP
RANZCP Medal of Honour 2021

Gordon Parker AO
Scientia Professor of Psychiatry, UNSW

Professor Julian Trollor
Head, Department of Developmental Disability Neuropsychiatry, UNSW
Sydney
President, Australian Association of Developmental Disability Medicine

Anne Kavanagh AM
Professor of Disability and Health, University of Melbourne
Co-Director, NHMRC Centre of Research Excellence in Disability and
Health

Leslie White AM
Emeritus Professor of Paediatrics, UNSW Sydney
Former Executive Director Sydney Children's Hospital
Inaugural NSW Chief Paediatrician

Rob Moodie
Professor of Public Health, University of Melbourne
Emerita Professor

Gwynnyth Llewellyn
Co-Director, NHMRC Centre of Research Excellence in Disability and
Health

Head, WHO Collaborating Centre for Strengthening Rehabilitation
Capacity in Health Systems

Fiona McKenzie

Chairperson, Council for Intellectual Disability

Ambassador 2009, Don't DIS My ABILITY

Kevin Stone AM, Chair

Catherine McAlpine, CEO

Inclusion Australia

Angus Graham OAM, Chair

Ellen Skladzien, CEO

Down Syndrome Australia

Naomi Lake

Health Ambassador, Down Syndrome Australia

Member, Roadmap Implementation Governance Group

Olivia Sidhu

Health Ambassador, Down Syndrome Australia

Member, Expert Advisory Group for Co-design of Centre of Excellence

Professor Christine Bigby

Director, Living with Disability Research Centre, La Trobe University

President, Australian Society on Intellectual Disability

Eileen Baldry AO

Deputy Vice Chancellor Equity, Diversity and Inclusion

Professor of Criminology, UNSW

Professor Michael McDaniel

Pro Vice-Chancellor (Indigenous Leadership and Engagement)

University of Technology Sydney

Graeme Innes AM

Former Disability Discrimination Commissioner

Past Chair, Disability Advisory Council of Australia

David Richmond AO

Former Secretary, Department of Health NSW

Damian Griffis

CEO, First Peoples Disability Network

Dwayne Cranfield

CEO, National Ethnic Disability Alliance (NEDA)

Mary Sayers

CEO, Children and Young People with Disability Australia

Sebastian Zagarella

CEO, People with Disability Australia

Ross Joyce

CEO, Australian Federation of Disability Organisations

Mary Mallett

CEO, Disability Advocacy Network of Australia

Leanne Wells

CEO Consumer Health Forum of Australia

Leanne Beagley

CEO, Mental Health Australia

Rachel Green

CEO, Sane Australia

Mark Orr AM

CEO, Flourish Australia

Carmel Tebbutt

CEO, Mental Health Coordinating Council NSW

Associate Professor Nathan Wilson

President, Professional Association of Nurses in Developmental
Disabilities Australia (PANDDA)

Laurie Leigh

CEO, National Disability Services

Jaquie Mills

Finalist Western Australian of the Year awards 2018

Managing Director, Microboards Australia

Jo-Anne Hewitt

CEO, Achieve Australia

Leanne Pearman

CEO, WA Individualised Services

Liz Forsyth

CEO, Northcott

Dani Fraillon

CEO, Get Skilled Access

Sam Paior

CEO, The Growing Space

Impact 25 Probono Award 2021

Morrie O'Connor

Co-ordinator, Community Living Association

Chair, ASID Queensland Division

Kerry Stubbs

Chair, Northcott Innovation

Andrew Richardson

CEO, Aruma

Gordon Trewern
CEO, Nulsen Disability Services

Claire Robbs
CEO, Life Without Barriers

Hayley Dean
CEO, Melba Support Services

Julia Squire
CEO, Ability Options

Margaret Bowen
CEO, The Disability Trust

Damon Williams
Partner, SAL Consulting

Joanna Quilty
CEO, NCOSS

Robert Tickner AO
Chair, Justice Reform Initiative

Catia Malaquias
Human Rights Award – Community Individual 2018
National Disability Award for Community Excellence 2017

The Hon Paul Stein AM QC

Former Chair of the Law and Justice Foundation NSW

Former President, Anti Discrimination Board of NSW

Emeritus Professor Terry Carney AO

Past President, International Academy of Law and Mental Health

Baden Offord AO

Emeritus Professor of Cultural Studies and Human Rights

Centre for Human Rights Education, Curtin University

Professor Patrick Keyzer

Dean of Law, Australian Catholic University

Roger West AM

Former President, Guardianship Tribunal NSW

Former Community Services Commissioner NSW

Chris Cunneen

Professor of Criminology, Jumbunna Institute for Indigenous Education and Research, University of Technology Sydney

Dr Mindy Sotiri

CEO, Justice Reform Initiative

Jonathon Hunyor

CEO, Public Interest Advocacy Centre

Dr Piers Gooding
Melbourne Law School, University of Melbourne

Dr Linda Steele
Senior Lecturer, Faculty of Law, University of Technology Sydney

Dell Stagg OAM
Chair, SA Council on Intellectual Disability

Mary Butterworth
CEO, Developmental Disability WA

Jodi Wolthers
CEO, Parent to Parent, Queensland

Jenny Dixon
General Manager, Speak Out Association of Tasmania

Arthur Bozikas OAM
CEO, Self Advocacy Sydney

Wendy Prowse
CEO, ADACAS Advocacy

Matilda Alexander
CEO, Queensland Advocacy Incorporated

Paige Armstrong
CEO, Queenslanders with Disability Network

Cherry Baylous
Disability Advocacy NSW

Janene Cootes AM
Executive Officer, Intellectual Disability Rights Service

Emeritus Professor Bruce Tonge
Former Director, Monash University Centre for Developmental
Psychiatry and Psychology

Catherine Franklin
Senior Research Fellow and Psychiatrist, Queensland Centre for
Intellectual and Developmental Disability

Dr Helen Beange AM
Founder, Developmental Disability Health Unit

Adj Associate Professor Bob Davis
Director Clinical Services, Centre for Developmental Disability Health,
Melbourne
Minister for Health General Practitioner Award 2014

Professor W Ted Brown
President, Fragile X Association of Australia
Former Director, New York State Institute for Basic Research (IBR) in
Developmental Disabilities

Professor Harry McConnell

Director Institute for the Clinical Advancement of Neuroplasticity,
Griffith University

Stewart Einfeld

Emeritus Professor, Brain & Mind Centre
University of Sydney

Teresa Iacono

Professor of Rural and Regional Allied Health, La Trobe University

Dr Jane Tracy

Former Director, Centre for Developmental Disability Health Victoria

Associate Professor David Harley

Public Health Physician

University of Queensland

Donna Best

Self-advocate

Convenor, Brisbane Hot Topics Group, Queenslanders with Disability
Network

Dr George Taleporos

Kirsten Deane OAM

Parent advocate

Jeanette Moss AM

Parent advocate and former Chair, Council for Intellectual Disability

Belinda Epstein-Frisch AM

Family advocate

Jeremy Ward

Parent advocate and first CEO, Queensland Advocacy Incorporated

Margaret Ward PSM

Parent advocate and past Deputy Chair, Disability Advisory Council of Australia

Alan Robinson

Advocate, WA

Christine Agius OAM

Northern Sydney Region Families and Friends of People with Disability

Professor Bruce Bonyhady AM

Executive Chair and Director, Melbourne Disability Institute, University of Melbourne

Professor Richard Bruggemann

SA recipient – Senior Australian of the Year 2021

College of Nursing and Health Sciences, Flinders University

Former CEO, Intellectual Disability Services Council, SA

Robert Griew

Former senior official,
Disability, Health and Education programs
State and Commonwealth governments

Susan Hayes AO

Emeritus Professor, Faculty of Medicine and Health, University of
Sydney

Trevor Parmenter AM

Professor Emeritus, Sydney Medical School
Past President, International Association for the Study of Intellectual
Disability

Professor Susan Balandin

Chair in Disability and Inclusion, Deakin University

Sally Robinson

Professor of Disability and Community Inclusion, Flinders University

Emeritus Professor John Taplin

Former Pro Vice-Chancellor International, University of Adelaide

Professor Angus Buchanan

Head of School of Allied Health
Curtin University

Professor Karen Fisher
Social Policy Research Centre, UNSW

Associate Professor Rhonda Faragher
Director, Down Syndrome Research Program, University of Queensland

Phil Foreman AM
Emeritus Professor and former Dean of Education, University of
Newcastle

Iva Strnadová
Professor of Special Education and Disability Studies and Academic
Lead Research, Disability Innovation Institute, UNSW

Professor Bronwyn Hemsley,
Head of Speech Pathology, University of Technology Sydney

Emerita Professor Patricia O'Brien
Faculty of Medicine and Health, University of Sydney
Former Director, National Institute for Intellectual Disability, Trinity
College, Dublin

Associate Professor Mary-Ann O'Donovan
Executive Director, Centre for Disability Studies, University of Sydney

Professor Jennifer Smith-Merry
Director, Centre for Disability Research and Policy
University of Sydney

Leanne Dowse

Emeritus Professor in Disability Studies, UNSW

Honorary Professor Kelley Johnson

Social Policy Research Centre UNSW and

School of Health and Social Development, Deakin University

Associate Professor Dinesh Joseph Wadiwel

Socio-Legal Studies and Human Rights

University of Sydney

Endorsements as at 2 March 2022