



Expert Reference Group – Implementation of the Assessment and Diagnosis of Autism Spectrum Disorders in Australia

DRAFT TERMS OF REFERENCE

1. Purpose and structure

The Expert Reference Group (the Group) will provide independent and expert advice to the Commonwealth Minister for Families and Social Services (the ‘Responsible Minister’) and the Commonwealth Department of Social Services (DSS) on the implementation of the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia* (the Guideline). For further information about the Guideline and implementation activities, refer to **Background information**.

The Group will support the Australian Government to:

- implement a nationally consistent approach (‘minimum national standard’) for assessment and diagnosis of autism and other neurodevelopmental and behavioural (NDB) conditions;
- support professionals involved in referral, assessment and diagnosis of autism and other NDB conditions to adopt the Guideline approach to improve diagnostic practices and consistency across Australia; and
- assist people with autism and NDB conditions, and their families and carers, to access clear information and comprehensive assessment that directs them to the right supports at the right time.

2. Roles and responsibilities

The Group will:

1. Provide clinical, academic and practical advice to support the Government to make informed decisions on supporting implementation of the Guideline. Advice may focus on:
 - a. strategies, processes and metrics for implementation;
 - b. the competency building and other support needs of target groups, including people with lived experience of autism, medical professionals, allied health practitioners, and other professionals potentially involved in identifying autism concerns and initiating a referral (for example teachers);
 - c. issues related to the implementation and application of the Guideline for people with other NBD conditions;
 - d. resources, tools and other actions to address identified needs;
 - e. feedback on progress and identifying areas for improvement in the Guideline implementation;
 - f. reviews or evaluations of the Guideline implementation; and
 - g. broader government policy goals and strategies to improve outcomes associated with Guideline implementation.
2. Drive activity to develop resources, tools and other actions to support implementation (‘implementation activities’).
 - a. Individual group members or sub-groups may volunteer to lead implementation activities (including targeted consultation and development of resources) to meet the identified needs of particular professions or other target groups.

- b. Activity leads will be asked to report regularly to the Group on the progress of implementation activities. Updates will generally be provided verbally at Group meetings.
3. Review documents, tools or resources to support the uptake of the Guideline. These may include:
 - a. strategic implementation documents; and
 - b. resources targeted at specific user groups, such as competency frameworks and other implementation activities that could facilitate the uptake and ongoing use of the Guideline within relevant professions.

3. Operational matters

Membership:

- The Group will be convened by a DSS Senior Official (DSS Convenor).
- Membership will comprise representatives from government, medical professionals, allied health practitioners, service provider and advocacy peak organisations, and people with lived experience of autism.
- The Group will understand the systems and processes that interact with autism assessment and diagnosis, and associated challenges and opportunities.
- DSS may review membership arrangements, subject to emerging issues, priorities and changing needs of the Australian Government.
- The Group may co-opt additional expertise, as required, including appointing 'special advisors' to facilitate the Group's access to other respected experts and leaders in the autism field.
 - With the DSS Convenor's prior approval, individuals and organisations may be invited to participate in Group discussions where they have particular knowledge, expertise or experience.
- Members will be appointed to the Group in an individual capacity. However, in providing advice, the Group members' role is to consult within their networks to the fullest degree possible (where appropriate).
- Where a consolidated view is required, the position of the Group should reflect the views of:
 - people with autism;
 - families, carers and friends of people with autism;
 - members of the disability, medical and healthcare sectors;
 - members of other professions involved in identification, referral, assessment and diagnosis of autism and other NBD conditions; and
 - relevant Australian Government agencies.
- Where a member is unavailable to attend a meeting, or fulfil other responsibilities as a member of the Group for a period of time, the member's designated proxy may participate in their stead.
 - Members delegating to a proxy must ensure that person has sufficient expertise and networks to represent the views of the profession or group represented by the member.
 - Proxies must be agreed by the DSS Convenor in writing.

Meetings:

- The Group will meet on a monthly basis between September 2020 and August 2021. Meetings will be primarily held by teleconference or videoconference. A small number of face-to-face meetings will be considered if appropriate and agreed by the Group.
 - a. To ensure continuity, members should be available to commit to monthly meetings between September 2020 and August 2021.
 - b. The forward schedule and other matters relevant to meetings will be determined at the first Group meeting.
- The DSS Convenor should be advised of a member's inability to attend a Group meeting as soon as is practical, and whether the member's proxy will attend in their stead.

Secretariat:

- DSS will provide the Group with Secretariat support to facilitate meetings and the development of implementation activities.

Reporting:

- The DSS Secretariat will provide a summary of the matters discussed at each Group meeting to members following each meeting.
- The DSS Secretariat will also maintain an Action Log for review at each Group meeting.
- Progress reports will be produced as required and a final report will be delivered after the term of the Group is completed.

Remuneration (sitting fees):

- Group members will be eligible for sitting fees for their time attending Group meetings, if they meet the following requirements:
 - They are not employees of the Australian Government; and
 - They do not receive a salary from their usual place of employment while participating in Group business.
- Payments to eligible members are made at the rates outlined in the Australian Government's *Remuneration Tribunal (Remuneration Allowances for Holders of Part-time Public Office) Determination 2019 (the Determination)* (<https://www.remtribunal.gov.au/offices/part-time-offices>) at:
 - section 11 – Other holders of part-time public office, and
 - section 20(1)(b) – Calculation of daily fees.
- DSS will arrange travel and accommodation for Group members and costs directly related to attendance at face-to-face Group meetings will be reimbursed by DSS, as appropriate.
- Flights and accommodation will be arranged by the DSS Secretariat in consultation with Group members.
- DSS will not pay any additional costs incurred for the Group members' private business.
- Reimbursement for other eligible travel-related expenses will be made once the required documentation is completed and returned by the Group member to the DSS Secretariat.

4. Other matters

Confidentiality:

- On occasion, Group members and proxies may be provided with confidential material. Members and proxies are not to disclose this material to anyone outside the Group and are to treat this material with the utmost care and discretion and in accordance with terms of their confidentiality agreement.
- Group members and proxies can seek advice from the DSS Convenor where they have queries about confidential information and circumstances in which it may be shared beyond the Group.

Conflict of Interest:

- Members must disclose to the DSS Convenor any situation that may give rise to a conflict of interest or a potential conflict of interest, and seek the DSS Convenor's agreement to retain the position giving rise to the conflict of interest, including an appropriate management strategy if required.
- Where a Group member gains agreement to retain their position on the Group, the member must not be involved in any related discussion or decision-making process.
- A Group member must not participate in Group business until a Deed of Confidentiality and Conflict of Interest declaration has been completed.

5. Proposed Membership

Convenor:

- DSS Senior Official

Government representatives:

- Department of Health, Department of Education, Skills and Employment, DSS, and the National Disability Insurance Agency

Professional societies – nominations sought from:

- General Practitioners: Royal Australian College of General Practitioners
- Paediatricians: Neurodevelopmental and Behavioural Paediatric Society of Australia
- Psychiatrists: Royal Australian and New Zealand College of Psychiatrists
- Psychologists: Australian Psychological Society
- Speech Pathologists: Speech Pathology Australia
- Occupational Therapists: Occupational Therapy Australia

Consumers – nominations sought from:

- Individuals on the autism spectrum: Autistic Self-Advocacy Network of Australia and New Zealand
- autism-specific service providers: Australian Autism Alliance
- Parents and caregivers: Autism Awareness Australia

Special advisors:

- The Cooperative Research Centre for Living with Autism (Autism CRC) (Guideline developer)

6. Forms to be completed

- Members who have accepted an invitation to be a member of the Group, may be required to complete the following forms:
 - Instrument of Appointment
 - Personal and Business Details, and Remuneration forms
 - Conflict of Interest Declaration
 - Deed of Confidentiality and Intellectual Property
- Documents will be provided to Group members by the DSS Secretariat and must be completed prior to attending Group meetings. Appointments to the Group will be finalised on receipt of completed required documents.
- Proxy members will be required to complete a Deed of Confidentiality. Members providing a nominated proxy, will be required to declare their proxy has no conflict of interest.
- Group members will need to return the original or scanned copies of the completed forms to the DSS Secretariat.

DSS Secretariat contact details:

DSS Secretariat

Ph: (02) 6146 5732

Em: AutismPolicy@dss.gov.au

Background information

Introduction

The National Guideline was developed by the Autism Cooperative Research Centre (Autism CRC), with funding from the National Disability Insurance Agency (NDIA) and released in October 2018. The development of the Guideline involved an extensive consultation process with people living with autism, their families and carers, clinicians, academics and policy makers. The Guideline was approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) under the *National Health and Medical Research Council Act 1992*. In granting approval NHMRC asserts that the Guideline has met its development standards, is high quality, is evidence based and has been developed with extensive consumer participation and public consultation.

The Guideline aims to create greater consistency in diagnostic practices across the Australia to ensure individuals on the autism spectrum and their families can receive optimal clinical care. The Guideline also emphasises the importance of listening to individuals and their families about the impact of the behaviours on family life.

The Guideline can be accessed at <https://www.autismcrc.com.au/knowledge-centre/resource/national-guideline>.

Implementation of the Guideline

Broad implementation of the Guideline across sectors and professions will help make the assessment and diagnosis of autism more consistent, transparent and accessible across Australia. This will ensure that people with autism have access to high quality assessment and receive the right supports, including entry to the National Disability Insurance Scheme (NDIS) if appropriate. The planned approach to implementation includes:

- development of educational and communication resources – the Autism CRC is currently leading this work with resources expected to be available by the end of 2020;
- establishment of an Expert Reference Group to provide expert technical advice to support implementation activities within the main professions;
- development of profession-specific resources, such as competency frameworks, to support diagnosticians to evaluate, and better align, their practice with the Guideline; and
- an evaluation to measure the impact and success of Guideline implementation.

The Expert Reference Group

The Government is committed to improving services and outcomes for children and adults with autism, including by supporting implementation of the Guideline. While take up of the Guideline to date has been encouraging, the continued contribution of individuals and organisations with expertise in autism assessment and diagnosis is critical to inform the work of DSS to implement the Guideline in clinical settings.

The Expert Reference Group will support the Government and DSS to make informed decisions about the implementation of the Guideline. Initially, the Group will be tasked with identifying and leading the development of profession-specific resources to build the competency of professionals in best practice autism assessment, as described by the Guideline. The Group will oversee implementation of the Guideline.