

## National Roadmap to Improve the Health and Mental Health of Autistic People

## Health Roadmap Working Group

The Health Roadmap Working Group (the Working Group) was formed in May 2023 to provide expert advice and oversee development of a National Roadmap to Improve the Health and Mental Health of Autistic People (the Roadmap).

In the first Working Group Meeting it was agreed the outcomes of the meetings will be released publicly. As the first two meetings were held within three weeks of each other, this contains a meeting summary of Meeting 1 and Meeting 2.

# Health Roadmap Working Group Meeting 1 (18 May 2023)

### Introduction

The Chair (First Assistant Secretary of the Primary Care Division, Department of Health and Aged Care (the Department)) opened the meeting by introducing the National Roadmap to Improve the Health and Mental Health of Autistic People (the Roadmap).

The Chair welcomed the members of the Health Roadmap Working Group (the Working Group) and gave an Acknowledgement of Country.

Four deputy co-chairs of the Working Group were also introduced, two of whom are Autistic. Meetings of the Working Group will be chaired by the Chair and two of the deputy co-chairs, one of whom will be Autistic.

The Chair acknowledged the Department is building on many years of work done by the autism community in developing the Roadmap.

Members were asked to declare any conflicts of interest that were not declared previously. None were declared. Members were asked to consider the Working Group Terms of Reference and provide feedback to the Secretariat via email.

## **Understanding Autism presentation**

The first item was a presentation by three Autistic people about autism, common experiences, and key considerations for engaging with the autism community. The Autism Cooperative Research Centre (Autism CRC) facilitated this presentation and provided support to the presenters.

The presenters shared their personal experiences, including key challenges they have faced as Autistic people. They also raised key issues with the health and mental health systems.

## Introduction to the Roadmap

The Australian Government has allocated \$1.5 million to develop the Roadmap. With this funding the Department will:

- develop a Roadmap that addresses issues faced by Autistic people in the health and mental health care system, and outline actions to improve outcomes
- support the Working Group
- engage in a co-design process, and

Roadmap is due to be finalised by December 2024.

 ensure all opportunities involving Autistic people will have appropriate accommodations available, including Easy Read and Auslan translations and closed captioning services as required.

The Australian Government has also committed to developing a National Autism Strategy (the Strategy), led by the Department of Social Services. The Roadmap will form part of the Strategy, but will also be a stand-alone document. The Roadmap and Strategy are being developed at the same time, which will help to ensure the Strategy has appropriate health and mental health content, and that relevant aspects of the Strategy are reflected in the Roadmap. Co-design will be a key feature of the Roadmap's development to ensure the voices of the autism community are reflected. The co-design process will focus on priority populations. The

## **Next steps**

Following the meeting, the Department emailed members asking for feedback on the Terms of Reference and ways that meetings could be made more accessible.

## Health Roadmap Working Group Meeting 2 (8 June 2023)

#### Introduction

The Chair opened the second Working Group meeting and gave an Acknowledgement of Country.

The meeting was chaired by the Working Group Chair, and two of the deputy co-chairs.

## **Previous meeting**

The meeting summary from 18 May 2023 was endorsed by members with no changes.

The Deputy Co-Chair noted the Terms of Reference had been updated based on feedback provided by members. Members provided further feedback, seeking updates to specify the group would not meet if there was not sufficient representation from Autistic people. It was agreed the Terms of Reference would be updated to explicitly state that meetings will not proceed without at least three quarters of the identified Autistic members being present.

Members were asked to nominate to be involved in a meeting to discuss requirements for the selection of an expert facilitator to conduct co-design sessions with Autistic people.

## Lessons learned from previous strategies

Autism Asperger's Advocacy Australia (A4) presented an overview on the lessons learned from previous disability, mental health, and autism strategies to inform the development of the Roadmap.

## **Evidence, policy and landscape mapping for the National Autism Strategy**

The Department of Social Services, as part of developing the National Autism Strategy, commissioned the Autism Cooperative Research Council to conduct an evidence review and synthesis of community views, research evidence and policy relating to key service domains that will be addressed in the Strategy.

Professor Dawn Adams and Dr Wenn Lawson presented on this research, with a focus on health and mental health services.

## **Discussion of Draft Guiding Principles and Elements**

The Department provided further context and background about the proposed structure of the Roadmap and introduced the key aspects of the structure, which the Working Group then discussed. They key aspects are as follows:

- Guiding Principles will be outlined in the opening to the Roadmap and will be considered throughout the entire Roadmap.
- Elements will form the outline of the Roadmap. Actions and outcomes will sit under each element. The Department has identified six Elements that aim to cover systemic issues which need to be addressed to improve the health and mental health of Autistic people. If required, additional Elements will be developed.

## **Next steps**

Following the meeting, the Department emailed members:

- The final version of the Terms of Reference, including a clear requirement on minimum numbers of Autistic representatives
- A survey to members to seek further and final comments on the proposed Guiding Principles and Elements.