

## Appendix A: Data indicators and template data record

### Purpose

The first output of the National project on sterilisation data collection practices is to develop and endorse a consistent set of indicators for collecting data on sterilisation applications and medical procedures that result in sterilisation of persons with cognitive impairment across all state and territory jurisdictions.

The purpose of Boards and Tribunals endorsing data indicators is to promote consistency across jurisdictions in relation to uniform data collection, where possible.

An excel data record template has been designed to capture this data. The objectives of the data record template are to:

- assist Boards and Tribunals to record data indicators as endorsed during the Office of the Public Advocate's National project on sterilisation data collection practices;
- to ensure uniform data can be easily collected and reported on request and;
- to assist with reporting annually to the Australian Guardianship and Administration Council
- to assist the Australian Guardianship and Administration Council to analysis data and report on cross-jurisdictional comparison where possible.

A glossary of terms is included below to assist Boards and Tribunals to report data in a consistent way.

### Background

Given the gravity of a decision to sterilise a person, in every state and territory the power to consent to such a procedure is vested in an independent Board or Tribunal (and in some jurisdictions, also the Family Court in relation to children).

Data indicators in relation to applications for sterilisation were developed and endorsed by the Australian Guardianship and Administration Council (AGAC) following the Federal Senate Community Affairs References Committee *Inquiry into Involuntary or coerced sterilisation of people with disabilities in Australia* (2013).

The inquiry raised concerns about the level of sterilisation of people with disability, a lack of uniformity, and a lack of data to determine the practices in relation to sterilisation that exist across the Commonwealth, states and territories. The Committee also noted that the data available suggests there is great scope for creating more consistent processes and outcomes across jurisdictions and sought consistent data recording and reporting across all Australian jurisdictions.

### Data indicators

AGAC has endorsed the following indicators for data collection purposes:

- Number of applications
- Age and age bracket of person
- Gender of person
- Primary disability of person
- Applicant
- Proposed procedure

- Alternative treatment/s considered
- Other parties to the application (including whether Public Advocate/Guardian is a party)
- Primary reason for application
- Outcome of application
- Date application received
- Date application heard
- Date decision made.

These indicators have been endorsed by the Board and Tribunals members of AGAC.

### Template data record

To enable Boards and Tribunals to easily collect this data an excel data record template has been developed and will be housed on the AGAC website. This data record template is contained on a separate document to this in excel format. These documents are to be read together. Instructions for use of the data record template are contained on tab 1 (Instructions) of the excel document (Template data record).

### Glossary of definitions

The data indicators require definitions to ensure consistent data recording.

**Applicant** - the person making the application

**Lawyer for adult with disability** – refers a to separate representative where appointed for the person by the Board or Tribunal or a lawyer representing the person at the request of the person or another party

**Other proposed procedure** – refers to where a second proposed procedure has been proposed

**Person** - the person with disability, decision-making impairment or mental incapacity to whom the application relates, sometimes referred to as ‘patient’ in legislation.

**Primary disability of person** – It is necessary to categorise primary disability to capture the different terminology that relates to disability as it differs markedly under the legislation in each state and territory. The categories under which Boards and Tribunals are to report are as follows:

- **Physical** - generally relates to disorders of the musculoskeletal, circulatory, respiratory and nervous systems
- **Sensory** - impairments in hearing and vision
- **Psychiatric** – mental ill health, mental illness. Includes a wide range of behavioural and/or psychological problems
- **Neurological** – includes degenerative conditions/disorders such as dementia, multiple sclerosis or Huntington’s disease
- **Acquired brain injury** – brain injury caused by accident or trauma, by a stroke, a brain infection or other drugs
- **Intellectual** - includes intellectual and developmental disability which relate to difficulties with thought processes, learning, communicating, remembering information and using it appropriately, making judgments and problem solving.

**Proposed procedure** – refers to the sterilisation procedure being proposed in the application. The proposed procedure must be irreversible. Sometimes there may be two proposed procedures.

**Sterilisation** - a surgical intervention that results either directly or indirectly in the termination of an individual's capacity to reproduce