

# Submission to the Committee on Supported Decision-Making for Adults with Disability and Older People in NSW

## Australian Community Industry Alliance (ACIA)

### 1. Introduction

The Australian Community Industry Alliance (ACIA) welcomes the opportunity to make a submission to the Committee's inquiry into supported decision-making for adults with disability and older people in New South Wales, pursuant to section 28B(1)(e) of the *Ageing and Disability Commissioner Act 2019*.

ACIA is the national peak body representing organisations that deliver community-based personal injury, disability and complex care services. ACIA administers the Australian Community Industry Standard (ACIS), a quality and safeguarding framework specifically designed for providers supporting people who have acquired disability, often through traumatic injury. This cohort includes people with acquired brain injury (ABI), spinal cord injury and other complex, lifelong impairments, many of whom receive funding through personal injury compensation schemes (such as workers compensation and motor accident schemes) and/or self-fund their care.

ACIA's submission focuses on the lived experience of this cohort and the unique supported decision-making challenges that arise where disability is acquired suddenly, systems are fragmented, and both individuals and their carers are new to navigating health, disability and social support environments.

### 2. Context: Acquired Disability and Supported Decision-Making

Unlike many people with lifelong disability, individuals who acquire disability through traumatic injury often experience an abrupt transition from independence to reliance on multiple service systems. For people with acquired brain injury in particular, changes in cognition, communication, insight and executive functioning can significantly affect decision-making capacity in nuanced and fluctuating ways.

In ACIA's experience, supported decision-making in this context is rarely a discrete or singular intervention. Rather, it is an ongoing, dynamic process that must adapt to: - changing functional capacity over time; - rehabilitation and recovery trajectories; - episodic impacts of fatigue, stress or mental health; - the involvement of multiple professionals and funding bodies; and - the evolving role of family members and informal carers.

This complexity places heightened importance on robust, well-understood supported decision-making frameworks that are consistently applied across systems.

### 3. Lived Experience of People Seeking Decision-Making Support (ToR a)

People with acquired disability frequently report that their decision-making is either insufficiently supported or prematurely substituted. Key themes include:

- **Inconsistent recognition of capacity:** Individuals may be assessed as lacking capacity in one system (e.g. financial or legal) while being expected to self-advocate and self-manage in others (e.g. service coordination or care planning).
- **Over-reliance on informal substitute decision-makers:** Family members are often defaulted into decision-making roles without adequate guidance, safeguards or recognition of the person's will and preferences.
- **Time-limited clinical settings:** Health and rehabilitation environments may prioritise risk management and efficiency over supported decision-making, particularly during acute and sub-acute phases.
- **Limited access to skilled support:** There is a shortage of practitioners with specialist expertise in supported decision-making for people with ABI and complex cognitive disability.

These experiences can result in loss of autonomy, disengagement from services, and erosion of confidence at a time when individuals are already navigating profound life changes.

### 4. Navigating Multiple Service Systems (ToR b)

ACIA members consistently report that one of the greatest barriers to effective supported decision-making is the fragmentation between systems, including:

- health and rehabilitation services;
- disability and community care providers;
- personal injury compensation schemes;
- financial and insurance systems; and
- social support, housing and employment services.

Each system operates under different legislative frameworks, risk tolerances, definitions of capacity, documentation requirements and accountability structures. For individuals with acquired disability, this fragmentation creates confusion and inconsistency in how decision-making rights are recognised and supported.

For example: - A person may be supported to make complex personal care decisions but be excluded from financial decisions about their own compensation or supports. - Scheme rules may unintentionally incentivise substitute decision-making to expedite approvals or manage perceived risk.

The absence of a shared, cross-sector understanding of supported decision-making undermines the intent of existing legislative safeguards.

## 5. Impact on Carers and Families New to Disability Systems

In the personal injury context, carers are frequently partners, parents or adult children who had no prior experience with disability or health systems before the injury occurred. These carers:

- are thrust into advocacy and decision-support roles with little preparation;
- may experience trauma and grief alongside new responsibilities;
- are often expected to interpret complex legal, clinical and funding information; and
- may be exposed to conflict where their views differ from professionals or scheme decision-makers.

Without structured support, education and safeguards, carers may unintentionally move from supporting decision-making to substituting it, particularly where systems default to expediency or risk aversion.

ACIA emphasises that supported decision-making frameworks must explicitly recognise and support carers, while maintaining the primacy of the person's will, preferences and rights.

## 6. Aboriginal and Culturally and Linguistically Diverse Experiences (ToR c)

ACIA recognises that Aboriginal people and people from culturally and linguistically diverse backgrounds face additional barriers in supported decision-making, particularly in the context of acquired disability. These include:

- culturally inappropriate assessment tools;
- language barriers and reliance on informal interpreters;
- mistrust of statutory systems due to historical and intergenerational trauma; and
- differing cultural norms around family, authority and collective decision-making.

Supported decision-making models must be culturally safe, flexible and capable of recognising collective and relational decision-making practices, particularly in Aboriginal communities.

## 7. Role of the Ageing and Disability Commission (ToR d)

ACIA supports the Commission's role in promoting safeguarding, rights and dignity. In relation to supported decision-making, the Commission is well placed to:

- provide authoritative guidance on best practice supported decision-making;
- promote consistency across service systems;
- educate providers, schemes and professionals; and
- monitor the inappropriate use of substitute decision-making.

However, ACIA members report limited practical guidance tailored to complex acquired disability and personal injury contexts.

## 8. Potential Enhancements to the Commission's Functions (ToR e)

ACIA recommends consideration of:

- explicit recognition of supported decision-making promotion as a core function of the Commission;
- development of sector-specific guidance, including for ABI and personal injury cohorts;
- enhanced education for scheme decision-makers and insurers;
- strengthened collaboration with health, justice and compensation regulators; and
- legislative amendments that reinforce supported decision-making as the default approach.

## 9. Ensuring Substitute Decision-Making Is a Last Resort (ToR f)

ACIA strongly supports the principle that substitute decision-making should only be used as a last resort, in limited and appropriate circumstances. Safeguards should include:

- clear evidentiary thresholds;
- time-limited and reviewable arrangements;
- mandatory consideration of decision-specific capacity;
- documentation of efforts to provide supported decision-making; and
- mechanisms to elevate the person's will and preferences even where capacity is impaired.

## 10. Conclusion

For people who acquire disability through traumatic injury, supported decision-making is not an abstract rights concept—it is central to dignity, recovery and participation. Fragmented systems, risk-averse practices and lack of shared understanding continue to undermine effective implementation.

ACIA urges the Committee to recognise the distinct experiences of this cohort and to recommend reforms that embed supported decision-making consistently across health, disability and personal injury systems, with appropriate support for carers and families new to these environments.

ACIA would welcome the opportunity to provide further evidence or appear before the Committee.