

## **National Disability Insurance Agency (NDIA)**

### **Consultation on Self-Directed Supports Registration**



Emerge Australia is the national patient organisation for people living with energy limiting conditions like myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and long COVID.

ME/CFS is a “serious, chronic, complex and multisystem disease that frequently and dramatically limits the activities of affected patients” (National Academy of Medicine, 2015). An estimated 45% of people diagnosed with long COVID meet the diagnostic criteria for ME/CFS.

Emerge Australia provides the following services and supports:

1. Evidence-based clinical education
2. Patient and carer telehealth support and information
3. Collaborative research via AusME Biobank and Registry
4. Advocacy impacting health and disability support policy

### **1. Do you agree with the definition of Self-Directed Supports?**

Emerge Australia agrees with the proposed definition of Self-Directed Supports. However, we note that some participants have expressed a desire for their arrangements with independent contractors to be explicitly included within the definition. This clarification would ensure that all relevant forms of self-directed support are appropriately recognised.

### **2. Do you agree with the proposed obligations for registered self-directed participants?**

Emerge Australia does not agree with the proposed obligations as they currently stand. While we acknowledge that self-directed participants effectively assume the role of employers, the obligations outlined are excessively burdensome. The National Disability Insurance Scheme (NDIS) and the NDIA should focus on empowering participants to lead fulfilling lives, rather than overwhelming them with administrative tasks.

If the NDIA insists on these obligations, it must provide significant support to participants. This support should include simple and accessible forms and resources, as well as tools such as salary award guides to assist in fair negotiations. Additionally, requiring participants to “undertake their own assessment for practice quality” is disproportionate, particularly for hiring services like cleaning or cooking. Such requirements undermine the principles of choice and control, which should allow participants to decide suitability based on their own needs and judgment.

While having a complaints process is reasonable, it is important to clarify whether this process is intended for employees. Suitability assessments should remain the participant’s prerogative, as they are in the best position to evaluate their support arrangements.

The proposed obligation about NDIA oversight is especially concerning. It appears to frame participant engagement as a means of sharing best practices and gaining support, but it instead comes across as an intrusive monitoring mechanism. This approach risks disempowering participants and creating a punitive dynamic. Ongoing monitoring should only occur during plan reviews, and not as an additional layer of compliance. Participants should have the freedom to continue arrangements that meet their needs without unnecessary scrutiny.

While some obligations are necessary to safeguard employer-employee relationships, many proposed measures feel excessive and do not align with the overarching goal of supporting participants.

### **3. Are there any barriers to compliance with these requirements?**

The proposed requirements are overly complex and do not consider the needs of participants with energy-limiting conditions like ME/CFS and long COVID. Compliance with such burdensome obligations would impose significant challenges.

#### **4. What features are important for the regulator to have when registering self-directed supports?**

The registration process should prioritise simplicity and efficiency. Key considerations include:

- A clear and accessible complaints process.
- Incident reporting mechanisms.
- A straightforward code of conduct for participants and their employees.

Beyond these measures, additional regulatory requirements should be kept to a minimum to avoid overburdening participants.

#### **5. How often should participants who self-direct their supports check-in?**

Mandatory check-ins should occur no more frequently than annually. However, participants should have the option to engage in more frequent check-ins if they desire additional support. These check-ins should be tailored to meet the needs of the participant, focusing on providing support rather than acting as a compliance exercise.

#### **6. What form should these check-ins take?**

Check-ins should be flexible and accommodate the participant's specific needs and circumstances. The format should be participant-driven and could include in-person meetings, virtual consultations, or written reports. The focus should be on understanding what is working well and identifying areas where the NDIA can provide additional support.

#### **7. What types of information could assist with check-ins?**

The NDIA should gather information directly from participants about their individual needs and experiences. Participants are best positioned to identify what information is most relevant to their self-directed arrangements.

#### **8. What types of support structures could help participants share innovative practices?**

Participants already share innovative practices through online communities and peer networks. What is lacking is direct support from the NDIA, such as:

- Assistance with setting up employment contracts.
- Guidance on reasonable wages and negotiating fair terms.
- Practical information about employer obligations, including occupational health and safety requirements.

These resources should be user-friendly and designed to reduce the administrative burden on participants.

## **General Feedback**

The proposed framework for registering self-directed participants lacks sufficient detail and risks becoming overly cumbersome. While the NDIA's intent to ensure safety and quality is commendable, the approach should prioritise participant empowerment and simplify compliance processes.

Currently, managing a NDIS plan already imposes significant administrative demands on participants. Many report that it feels like a full-time job. Adding further obligations without corresponding support will only exacerbate this issue. The NDIA's role should be to facilitate participants' ability to live fulfilling lives, not to impose additional layers of bureaucracy.

While a framework is necessary to ensure safety and accountability, the NDIA must focus on providing accessible tools and support to enable participants to meet these requirements easily. Check-ins, in particular, should not be punitive or intrusive but should be framed as an opportunity to identify and address challenges collaboratively.

Emerge Australia urges the NDIA to adopt a participant-centred approach, starting with the assumption that most participants are doing their best to meet their obligations. By shifting the focus from compliance monitoring to genuine support, the NDIA can better align with the principles of the NDIS.