27 August 2026

Inclusive Communities Fund Consultation
Department of Health, Disability and Ageing
GPO Box 9848
CANBERRA ACT 2601

Dear Department of Health, Disability and Ageing

Re: Emerge Australia submission on the Inclusive Communities Fund Consultation

Emerge Australia welcomes the opportunity to respond to the Inclusive Communities Fund (the Fund) Consultation. Emerge Australia is the national patient organisation for people living with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and long COVID. We provide education, support and advocacy to the more than 600,000 Australians affected by these conditions, and we work with clinicians, researchers and governments to improve diagnosis, management and quality of life for our community.

This submission focuses on NDIS participants living with ME/CFS or long COVID. To gain access to the NDIS, a person with either condition must demonstrate permanent and substantial functional impairment. In practice, participants with ME/CFS or long COVID will generally be severely affected and mostly housebound or bedbound. They commonly experience brain fog, post-exertional malaise, sensory sensitivities and comorbid conditions such as postural orthostatic tachycardia syndrome (POTS), among many more symptoms, all of which significantly affect functional capacity.

For the NDIS participants represented in this submission, opportunities for community participation are extremely limited. Many are able to leave home only occasionally and must prioritise essential tasks such as attending medical appointments or obtaining groceries. Others cannot safely leave their home or bed at all. In-person attendance at a community activity is therefore rarely realistic for this cohort, regardless of how accessible or welcoming the activity is. A more ‘inclusive’ sports club, theatre group or arts organisation remains out of reach if a participant cannot safely attend the venue.

We welcome the Australian Government's investment in community inclusion and support the intent of the Fund. However, we have significant concerns about the sequencing and framing of this consultation, and about whether an organisational capability-building model, on its own, can deliver the outcomes the Fund is seeking for NDIS participants with energy-limiting chronic illness such as ME/CFS and long COVID. Emerge Australia recommends a complementary model that protects essential individual supports like attending medical appointments or grocery shopping, while funding community organisations to provide remote, flexible and low-exertion participation, developed and evaluated in partnership with disability-led and patient organisations.

1. This consultation cannot be considered in isolation from cuts to individual funding

The Consultation Paper notes that ‘there are other changes expected to happen to NDIS funding for Social, Civic and Community Participation supports and Capacity Building Daily Activity supports’ and states that these changes ‘are not the focus of this paper’. These processes cannot be meaningfully assessed in isolation because their combined effect will determine whether participants experience greater or reduced inclusion. Although the detailed design of individual NDIS funding is outside the stated scope of this consultation, its interaction with the Fund is directly relevant to whether the Fund can achieve its intended outcomes.

Feedback received from Emerge Australia's community indicates that NDIS participants with ME/CFS and long COVID commonly use their Social, Civic and Community Participation (SCCP) funding for essential activities far

more often than for social engagement. Participants particularly report using it for transport and support to attend medical appointments and obtain groceries. Participants are already struggling to make this funding stretch, so the confirmed 50 per cent reduction in SCCP funding will, for many in our community, mean missing medical appointments or being unable to shop for food, not simply fewer social opportunities.

> *"If I didn't have funding, I wouldn't have the ability to attend allied health and medical appointments and I'd likely deteriorate and end up needing more support."*
>
> - NDIS participant living with ME/CFS

Without access to necessary medical care, manageable symptoms may go untreated, increasing the risk of deterioration and further loss of function. Community feedback also shows that many participants use SCCP funding for a support worker to assist with grocery shopping, a task requiring planning, mobility and stamina beyond what they can manage alone. A 50 per cent reduction is likely to force these participants to choose between attending a medical appointment and obtaining food.

Some participants with ME/CFS or long COVID have also been able to use SCCP funding for social engagement, for example, to have a support worker help them to attend an event with friends or family, sometimes for the first time in many years. As essential activities absorb the reduced SCCP funding, this social use is likely to be the first to go, as these participants will have to prioritise medical appointments. That is a genuine loss of community connection that funding provided only to community organisations cannot replace.

This underlines why the people affected by the reduction in SCCP funding cannot simply be served by a more accessible community sector. Organisational funding can make an activity more welcoming and flexible, but most participants with ME/CFS or long COVID are unable to attend physical events, and those that do would not be able to without funding for a support worker to assist them. Treating the Fund as an offset for reduced individual choice, control and essential support would therefore use the wrong policy tool for this cohort and would not improve their outcomes.

Losing this funding represents a significant loss of essential support for our community. We accept that this may be an unintended consequence of a reduction aimed at social and recreational spending, rather than the essential activities for which participants report using the funding. We recommend that support for essential activities, including transport and assistance to attend medical appointments and obtain groceries, be assessed and funded individually as essential support, rather than being subject to a global percentage reduction. We ask the Department to refer this recommendation to the area responsible for the associated NDIS funding reforms and ensure that the Fund and those reforms are assessed together. Participants should not be forced to choose between medical care, food security and community connection, and the Fund should not be characterised as compensating for the loss of individual support.

2. Making invisible disabilities visible in the Fund

The examples of community activities and barriers discussed in the Consultation Paper focus heavily on physical accessibility and attitudinal barriers connected to visible disability. ME/CFS and long COVID are energy-limiting chronic illnesses with an invisible presentation. Feedback received by Emerge Australia indicates that community organisations, including well-meaning ones, frequently do not understand post-exertional malaise, the need to cancel or reschedule at short notice, or the risk that overexertion during a single activity can cause a relapse lasting weeks or months.

For many people with ME/CFS and long COVID, the central access barrier is post-exertional malaise (PEM). PEM is a worsening of symptoms and functional capacity following physical, cognitive, social or emotional exertion. The effects of PEM are often delayed and can last days or weeks, so an activity that seems manageable at the time can still cause a significant deterioration afterwards. This means accessibility cannot be judged only by whether someone was able to attend an activity, but by whether they were able to participate without lasting harm to their health.

We recommend the Fund's design and any associated guidance material explicitly reference invisible disabilities, especially energy-limiting and fluctuating chronic illness, including ME/CFS and long COVID, as a distinct access consideration, separate from mobility or sensory access. Training funded under the Fund should go beyond a single information session and instead build organisations' capacity to offer flexible attendance (for example, no-penalty cancellation, hybrid or online options, shorter or self-paced formats, and the ability to rest during an activity) as standard practice.

3. Housebound and bedbound people must be a priority, and participation defined broadly

The Consultation Paper's examples of community activities; joining a sports club, theatre group, community garden, volunteering group or multicultural organisation, are, without exception, based on attending a physical venue. This model does not reach the population this submission is concerned with: people with ME/CFS or long COVID who are housebound or bedbound. For this group, in-person attendance is rarely achievable, regardless of how accessible, welcoming or well-adjusted an organisation becomes.

Individual supports remain essential for participants who can leave home occasionally with assistance. However, for participants who are unable to leave home or bed, individual assistance alone cannot make venue-based participation possible. What the Fund can control is whether ‘community participation’ continues to be defined, implicitly or explicitly, as something that happens at a venue.

Housebound and bedbound participants should not be treated as outside the scope of the Fund simply because they cannot participate in traditional, venue-based ways, especially when their individual SCCP funding is being reduced by 50 per cent. We recommend that the Fund explicitly recognise them as a priority cohort and define ‘community participation’ broadly enough to include remote, hybrid, home-based and asynchronous forms of connection, for example:

- online groups
- activities with genuine opportunities for remote participants to contribute rather than only observe
- recorded or asynchronous content
- peer connection models built around limited and fluctuating energy.

For this cohort, remote and asynchronous participation should be treated as the primary channel of inclusion.

4. Funding design must support genuine co-design and sustainable access

Disability-led and condition-specific organisations should be eligible to receive Fund grants, including as lead applicants where appropriate. Their role should not be limited to providing unpaid advice to mainstream community organisations. Funding arrangements should fairly remunerate lived-experience expertise and support ongoing partnership throughout design, delivery and evaluation.

The Fund should also recognise that accessibility is not achieved through one-off training alone. Hybrid platforms, captioning, accessible communications and the staff time needed to deliver flexible formats involve ongoing costs.

These costs should be eligible for funding so that accessibility improvements can be embedded in standard practice and sustained after the grant period ends.

5. Response to consultation questions

What community activities would you like the Fund to support?

- Activities with online participation options, where people joining online are included and able to participate just as fully as those in the room.
- Peer-led and peer-informed activities, recognising that connection with others who understand energy-limiting illness is itself a form of meaningful community participation.
- Low-sensory, low-exertion activities (for example, quiet arts, craft, writing or discussion groups) alongside more active options, so community participation is not defined by physical activity alone.

Have you faced barriers to participating in organisations in your community? What would help you take part in the future?

- Feedback received from NDIS participants with ME/CFS and long COVID identifies the lack of suitable online participation options as a major barrier to community involvement.
- Funded support to participate from home is required: technology, communication assistance, and help sustaining connection with others over time.

What support, resources or changes would help organisations become more inclusive and accessible for people with disability?

- Practical, condition-specific education (not generic disability awareness training) developed with input from disability-led and patient organisations, including those representing energy-limiting and chronic illness such as ME/CFS and long COVID.
- Support to redesign activity formats (timing, duration, intensity, and cancellation policies) rather than only physical or communication adjustments.
- Ongoing, rather than one-off, partnership arrangements with disability-led organisations, so inclusive practice is embedded and reviewed over time.

What role could local governments play in supporting community inclusion?

- Local councils can help by ensuring community facilities, libraries and programs they operate offer flexible-format and low-sensory options, and by connecting local organisations with disability-led groups for training and partnership.

What is the best way for community organisations to build meaningful and lasting inclusion, and how can the benefits continue after the funding period ends?

- Embedding flexible, low-exertion participation options into an organisation's standard programming (rather than as a one-off adjustment) is more likely to be sustained after funding ends than a single training session.
- Lasting partnerships with disability-led organisations, including patient organisations for energy-limiting and chronic illness, should be a funding condition, with a mechanism for organisations to seek further advice after the grant period.

How can we make sure the Fund works well for all people with disability?

- People living with ME/CFS and long COVID who also face other barriers, such as living in regional, rural or remote areas, having a low income, or being a child or young person, often experience compounding

isolation. Equity criteria should prioritise people facing multiple, intersecting barriers, not just fund the activities that are easiest to deliver.

- Digital exclusion (unreliable internet, cost of data, lack of suitable equipment) should be considered when designing remote participation options, so hybrid and online formats do not create a new barrier for some people while removing one for others.

6. Success should be measured by participation outcomes, not organisational activity

We are concerned that the Fund's success will be measured by outputs such as the number of grants awarded, organisations trained, partnerships formed or activities offered. These measures can look positive while telling us little about whether participants experienced improved inclusion.

For our community, a meaningful measure of success includes whether people could participate within their energy limits and without triggering PEM; whether attendance and participation expectations were genuinely flexible; whether remote or home-based participation was available and treated as equally valid to in-person attendance; and whether improvements were sustained once the three-year funding period ended. Evaluation should also capture the experience of people who tried and were unable to participate, or who chose not to attend because the format was unsuitable, not only the experience of those who successfully attended. Without this, the Fund risks reporting success while the people it is least reaching remain invisible in the data.

7. Recommendations

- Acknowledge in the final Fund design that organisational capability building and individual support serve different, complementary purposes, and that community organisations cannot deliver equivalent inclusion outcomes for NDIS participants who are mostly housebound or bedbound if their individual SCCP funding is reduced.
- Refer to the area responsible for the associated NDIS funding reforms the recommendation that support for essential activities, including transport and assistance to attend medical appointments and obtain groceries, be assessed and funded individually as essential support, rather than being subject to the 50 per cent reduction in SCCP funding.
- Do not position organisational capability building as a substitute for individually held funding, choice and control. Assess the combined impact of the Fund and reductions in individual funding on participants' health, safety and inclusion outcomes.
- Explicitly name energy-limiting and fluctuating chronic illness, including ME/CFS and long COVID, as a distinct access consideration in Fund guidance and eligible activities, so NDIS participants with these conditions are not overlooked.
- Require funded organisations to build flexible attendance and low-exertion formats into standard practice, not as an isolated adjustment.
- Involve patient and disability-led organisations representing energy-limiting and chronic illness, including ME/CFS and long COVID, in the ongoing design, delivery and evaluation of the Fund.
- Make disability-led and condition-specific organisations eligible to receive Fund grants, including as lead applicants where appropriate, with budgets that fairly pay for lived-experience expertise and co-design input rather than relying on unfunded partnership.
- Allow funding to cover the reasonable, ongoing costs of implementing and maintaining accessibility improvements, such as hybrid participation platforms, captioning, or staff time to run flexible formats, not only one-off training or advice, so that improvements outlast the grant period.

- Recognise people who are housebound or bedbound as a priority cohort, and define community participation broadly enough to include remote, hybrid, home-based and asynchronous forms of connection.
- Measure the Fund's success by participation outcomes, whether people could take part safely, sustainably and on their own terms, rather than by the number of organisations trained or activities offered.

An inclusive community is not one that simply opens its doors wider. It is one that recognises that, for some people, connection will never come through a door at all, and funds accordingly.

Thank you for considering this submission. Emerge Australia would welcome the opportunity to discuss these issues further, including through a phone consultation or by providing further evidence from our membership.

Yours sincerely

Emerge Australia