



## FORUM

# The NDIS for people with brain injury ensuring “*choice and control*”

## Summary of Themes

- **Current views of and concerns about the NDIS**
- **Will services change or improve under the NDIS?**
- **Planning, setting goals and service delivery**

# Summary of Themes

## Current views of and concerns about the NDIS

1. Implementing the National Disability Insurance Scheme (NDIS) requires a major shift for disability service providers - from relying on their own views about the services that ought to be provided to people with disability to now arranging their services to provide the supports that NDIS participants want to help achieve their goals.
2. Being an NDIS participant also requires a shift for people with acquired brain injury (ABI) as there is a presupposition in the NDIS "choice and control" approach that participants already have the information and tools available to choose and control the supports they require.
3. For NDIS participants with an ABI there is a need for advocacy and support on goal-setting, planning, choice of support providers and implementation of supports.
4. The different language used in the health and disability sectors means that there is confusion about what is funded under the NDIS and whether once people with an ABI complete their rehabilitation they will receive appropriate and ongoing support to gain as much independence as possible. The NDIS does fund skills development for people with disability to increase their social and economic participation. In the health sector this is called rehabilitation, which is not funded by the NDIS. However, both rehabilitation and the NDIS aim to promote as much independence and social and economic participation as possible. Rehabilitation services do this at an earlier stage. NDIS continues over the person's lifetime.
5. Evidence from other jurisdictions suggests that people with acquired brain injury are less likely to adopt individualised funding, let alone take up self-management. With the NDIA aiming for around 30 per cent of scheme participants self-managing their plans this will require significant upskilling of participants with an ABI.

## Will services change or improve under the NDIS?

1. Significant expertise and knowledge about ABI already exists in rehabilitation and in the specialist disability services sector. There is concern that National Disability Insurance Agency (NDIA) planners and Local Area Coordinators are unlikely to have sufficient expertise and knowledge to appropriately assist people with an ABI set goals and develop their plans. This speaks to the need to build workforce capacity throughout the NDIS for persons with disability with higher and/ or more complex levels of need.
2. The aim of the NDIS is to support people with disability to expect choice of support providers and control over their supports with these supports being person-centered not service-centered, and that services providing disability supports actively encourage participant engagement.

# Summary of Themes

3. The aspiration of the NDIS is that the more participants want particular supports, the more services will need to change to meet this demand. Is there a risk that people with disability will accept 'more of the same' which would mean there was no incentive for services to change? This may depend on how much support is available to enable a graduated introduction to choice with supports available to assist participants in making choices and decision-making from a selection of available support providers.
4. For many people with an ABI their entry into the NDIS will be from the health sector, but not for all. There are people with an ABI now without disability supports who will become eligible for the NDIS. For example, people with ABI who are in the prison system or who are homeless. The NDIS's approach to access appears to be "build it, and they will come". Local and international evidence suggests that uptake of individualized funding by people with an ABI will be both low and late. The NDIA, especially in its planning for the architecture of Information, Linkages and Capacity-Building (formerly "Tier 2") supports and services, needs to re-commit to outreach with "hard to reach populations", inclusive of people with an ABI.

## Planning, setting goals and service delivery

1. To be effective, there is a need for advocacy and support for people with an ABI seeking to access the NDIS, in goal-setting and planning and in making a meaningful choice between providers competing for participant funding.
2. For people with disability to be active consumers, in having control and making choices, the power which rests with professionals now needs to be shared. Otherwise the plan is little more than a "professional" tool with limited or no ownership by the person with disability.
3. For goal setting and planning to be "in the hands" of the person with disability, planners need very specific skills to actively listen to participants, and to respect their goals and work with the person so that the goals set are owned by the participant, are achievable, flexible and short-term with opportunities for regular review and revision - as goal-setting should be an ongoing process with graduated goals from short to medium to long-term. Given the challenges to goal-setting and planning specific to ABI, Agency planners and Agency-funded Local Area Coordinators should be given training in the fundamentals of ABI.
4. At this time in the transition phase of the NDIS, participants' "My First Plan" is likely to be the same as their current plan with planning limited to immediate needs and gaps in service and support provision and aspirational goals deferred until subsequent plans.
5. At all stages in planning, planners need to be skilled in understanding (often) invisible difficulties with attention, understanding, memory and other cognitive difficulties or mental health problems which may affect initial discussions, planning, and implementation and review of plans.