



Inclusion Australia

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Contact:

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Inclusion Australia (NCID)

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To the Commissioners,

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Please find attached Inclusion Australia (NCID)'s submission.

We would like to thank the Commission for the opportunity to make a submission and hope you enjoy reading our submission.

Yours sincerely

Jesse Matheson
Secretariat Officer
Inclusion Australia (NCID)

Draft Finding 2.1

Scale and pace of NDIS rollout to full scheme is highly ambitious. It risks the NDIS not being able to implement the NDIS as intended and it poses risks to the financial sustainability of the scheme

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) would not support slowing down the roll out to respond to the challenges of implementation. Rather, we would recommend clarifying the most critical issues which require resolution, prioritise those issues and implement proactive strategies in partnership with stakeholders to respond to those issues. Only when a strategic and co-ordinated approach to supporting the rollout has been considered and explored should the option of slowing down is to be considered.

Given Inclusion Australia (NCID)'s specific focus in this response on people who require complex support, we believe that a co-ordinated transition strategy for this cohort that covered the range of transition issues including pre-planning support, ILC preparation for transition, skilled planners, targeted market development may resolve the issue without slowing down the roll out. Alternatives such as changes to resourcing could be addressed in more detail by the Commission.

Inclusion Australia (NCID) is concerned that there does not currently seem to be sufficient sensitivity within the Scheme for people who require complex support or a full understanding of the particular costs and that this further puts financial sustainability and quality of outcomes at risk.

Draft Finding 2.2

NDIA projections of Scheme costs are broadly consistent with the Productivity Commission's 2011 modelling

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) suggests that particular cost variances between projected and real costs would benefit from further understanding. In particular we note the discrepancy between projected costs for those with the lowest level of function, and that while those with packages make up only 18% of participants but more than 50% of costs.

We would suggest that this reflects that planning might not be adequately understanding and responding to people's true needs, might not be taking into account contemporary evidence based practice, and might not be reflecting the insurance based principles as they could apply here.

Inclusion Australia (NCID) also recommends that greater analysis of reference packages be undertaken to ascertain whether or not the NDIS prices is adequately sensitive to costs for people who require complex support, and in particular whether or not the current measure of function adequately caters for the kind of skills and expertise and up-front work required for this cohort.

Draft Finding 2.3

NDIS came in under budget at the end of the trial. In large part this was due to a utilisation rate of 74%

The NDIA has put in place initiatives to address cost pressures. It is too early to assess the effectiveness of these.

Inclusion Australia (NCID) Response

Given the percentage of people with ID in the Scheme, and the percentage of NDIS costs amongst those with lowest function, it would appear likely that people with complex needs made up a significant part of that. The lower utilisation rate might reflect the lack of availability of supports.

Inclusion Australia (NCID) notes that one of the initiatives to address cost pressures has been the First Plan process. We would contest that this has had a detrimental effect on people who require complex support, and that this detrimental effect will increase cost pressures down the track – consistent with insurance based principles.

Poor plans not based on a thorough understanding of the principles and evidence regarding complex support needs and challenging behaviour coupled with a thin market and lack of supporting infrastructure means that supports are not having a positive impact and for some might in fact have a detrimental impact meaning that costs will escalate because needs will not be met and will increase as people's situations deteriorate rather than improve.

Draft Finding 2.4

Not all participants are benefitting from the scheme. Participants with psychosocial disability, and those who struggle to navigate the scheme are most at risk of experiencing poor outcomes

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) recognises that for most people with an intellectual disability and their families and carers the NDIS has resulted in increased choice and control and opportunity.

Inclusion Australia (NCID) is however concerned that people with complex support needs (who often also have mental health issues) are not benefitting from the Scheme.

Inclusion Australia (NCID) recommends a dedicated transition strategy specifically for this cohort given their particular vulnerabilities and risks.

Such a strategy should look at all elements required to make the Scheme successful for this group including ensuring pre-planning support and capacity building, workforce and sector capacity building needs to ensure good quality services, and individual and systemic measures to ensure mainstream services fulfil their obligations to this group (who by their very definition tend to be more likely to be across service systems).

Draft Recommendation 3.1

When determining eligibility under the disability requirements, the Agency should collect data on which of the activity domains are relevant for each individual

Inclusion Australia (NCID) Response

If the collection of this data does not add any burden to peoples' access to the scheme such as further evidence having to be provided, then IA can see the benefits of collecting this data.

It would assist in helping us to better understand the needs of participants but should also assist with analysis of the data in order to monitor how population groups with certain experiences of disability are faring under the Scheme.

Information Request 3.1

Feedback on advantages and disadvantages of maintaining List D – Permanent Impairment/Early Intervention, Under 7 years – No Further Assessment Required

Inclusion Australia (NCID) Response

Anything that reduces burden and increases access is good. Especially for groups like FASD who have historically tended to miss out. But recognise the need for sustainability.

But to draw a line requires a degree of confidence that you can say who is and who is not likely to benefit from early intervention – and how much benefit makes it worthwhile?

We want to maximise development in those early years and make sure that anything post intervention in education is very positive. This is a huge interface issue because it speaks to what role do schools play for kids with more complex needs. And where do therapeutic services ongoing sit.

Also, are our expectations of early intervention and how quickly it shows benefits always reasonable? And is there proper post-early intervention support so people sustain the benefits.

Information Request 4.1

Is the NDIS Act sufficiently clear about how or whether the 'reasonable and necessary' criterion should be applied? Is there sufficient clarity about how the section 34(1) criteria relate to the consideration of what is reasonable and necessary?

Is better legislative direction about what is reasonable and necessary required? If so, what improvements should be made? What would be the implications of these changes for the financial sustainability of the scheme?

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) would not recommend prescribing reasonable and necessary in any greater detail in legislation as this would certainly reduce flexibility and responsiveness and also innovation.

If the intention is to provide greater clarity to participants and planners then there are other ways to do this. For example, mechanisms for sharing amongst planners and participants the kinds of things that are included in plans for various kinds of goals and needs would help to ensure there are more consistent expectations. And work with planners to increase consistency. Independent advocacy support to participants to assist them to negotiate what is reasonable and necessary must also be available. Independent advocacy funding, separate to the NDIS, must be secure to enable its vital contribution to the overall success of the scheme.

Reasonable and necessary is effectively a negotiation – and people need good quality information and also good support if they are to negotiate equally. So good access to advocacy and other support to people in their planning conversations by people who are independent of the NDIS system is important.

If the intention is to pin things down by enshrining in law what can and cannot be provided so that it is not contestable via the Courts then it is likely that this would significantly hamper flexibility and by default reduce choice and control.

Information Request 4.2

Should the NDIA have the ability to delegate plan approval functions to Local Area Coordinators? What are the costs, benefits and risks of doing so? How can these be managed?

Inclusion Australia (NCID) Response

The priority in making decisions about how plans should be approved must be based first on ensuring the quality of the plan for the individual (the risk to the participant), secondly on ensuring the sustainability of the scheme (the risk to the Scheme), and thirdly on ensuring the administrative efficiency. Noting of course the robust review and appeal mechanism that sits alongside the planning and decision making process.

It would stand to reason that plans that are simple and relatively low in cost and where risk to the participant and the Scheme is lowest should be able to be approved in the most straightforward way possible.

Where there is a greater level of risk to the participant and also to the Scheme then perhaps a higher level of delegation is required.

A person with more complex needs is at greater risk of a poor plan. They need more pre-planning preparation, planners with a different kind of expertise and knowledge base. If a plan does not adequately reflect their needs, they are less likely to have a voice in challenging it and they are more likely to have an adverse outcome. The Scheme is then at a greater risk because their long term costs are likely to be greater and the outcomes achieved less positive.

It would stand to reason that a plan that has a higher level of risk should have a higher level of delegation both in terms of compliance but also quality of the plan. The NDIA's proposed intensive planning practice guide seems to include some effort to provide oversight from a quality point of view by ensuring that people with expertise are reviewing plans.

By reducing the number of plans requiring a higher level of delegation, this should free up some capacity for those with the delegation to focus on the quality of the plans.

(Response continued on next page)



In Western Australia's administered system where LAC's (or LC's) are roles within the decision making body plan approval functions are delegated based on the value of the plan. Lower plan funding amounts are able to be approved by LACs. The higher the cost of the plan, the higher the delegation required to approve a plan.

There has been some anecdotal feedback that LC's in WA have been working to keep plans within lower levels of delegated authority so that they can be signed off simply and easily without needing to be escalated and without having closer scrutiny, so this might potentially create an adverse incentive to keep plans lower than they might otherwise be. But if people had good quality support in their planning and clear understanding about review and appeal mechanisms any adverse consequences could be avoided.

Delegation of planning inherently presents a certain level of risk to the Agency and to the sustainability of the Scheme by decreasing the level of direct oversight and control the Agency has on costs. But that risk can be managed in terms of which plans it is decided to delegate based on cost. The benefits of delegation are that they increase efficiency by ensuring that Agency administrative resources are then focussed on those plans that represent the greatest risk – for participants and the Scheme alike.

Risks of planning decision to individuals can be balanced by ensuring access to quality independent planning support and advocacy, good pre-planning work, quality planners with sound knowledge of disability and a robust appeals and review mechanism.

Draft Recommendation 4.1

NDIA should:

- *Implement process for allowing minor review amendments and adjustments to plans without triggering a full plan review;*
- *Review protocols on how phone planning is used;*
- *Provide clear, comprehensive and up to date information about how the planning process operates, what to expect during the planning process, and participants' rights and options*
- *Ensure that LACs are on the ground six months before the scheme is rolled out in an area and are engaging in pre-planning activities*

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) supports any mechanism that will genuinely improve the quality of the planning process and the responsiveness of plans for people with intellectual disability, including those who require complex support.

Inclusion Australia (NCID) sees no objection for making it simpler to allow minor changes to plans without requiring a full review if they will help assure that plan is meeting an person's needs. It makes flexibility and responsiveness easier for the person, and the Agency and would reduce an administrative cost.

Inclusion Australia (NCID) absolutely supports a comprehensive review of how phone planning is used, and we would in fact not recommend the use of phone planning for people who require complex support at all – unless that was their express wish. The phone planning process is inherently flawed for this group as it risks important information being missed, it doesn't allow for a person to be sufficiently supported during a planning conversation. Important cues and triggers that can be gleaned from a skilled face to face planning conversation are lost.

It undermines the kind of rapport, trust and relationship that is critical in a planning conversation. We would contest that phone planning only be used for very simple plans or where extensive pre-planning work has been undertaken in developing a person's plan.

Clearer information about planning process, what to expect and rights and options should be routinely available to people at all stages of the process – including actively promoting disability consumer and advocacy organisations that might be able to assist or support them and referring.

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LACs and other ILC related activities to assist with pre-planning should be underway prior to rollout. People who require complex support have the greatest capacity to benefit from good quality pre-planning – but that pre-planning must be delivered in an informed way either through skilled LACs with experience engaging and planning with this cohort.

Alternatively, other organisations with an established track record of engaging with this cohort should be actively engaged in delivering ILC initiatives focussed.

Inclusion Australia recommends that as part of a dedicated rollout strategy for people who require complex support a specific pre-planning approach be considered. This would include ensuring availability of LACs who have skills and experience in working with this group and developing other ILC strategies to be delivered by organisations with experience in working with these groups.

Draft Recommendation 4.2

NDIA should ensure that planners have a general understanding about different types of disability. For types of disability that require specialist knowledge there should be specialised planning teams and/or more use of industry knowledge and expertise.

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) supports the call for specialist planners and recommends the use of specialist planners for people who require complex support. Planners working with people who require complex support need to understand the nature of complex support and be up to date with contemporary understandings and approaches to complex support.

These planners need to understand the principles of positive behaviour support. The need to have a good grounding in the key ingredients for learning (time, engagement, active instruction, reinforcement, in the person's own world). They need to understand the unique issues for people 'on the fringe' who might appear to have a lower level of disability but whose functional impairment is exacerbated by the complexity of their life experiences and other needs.

These planners need to be very grounded in a preventative and early intervention approach that understands how important it is to create the right environment for a person via the plan that will minimise the risk that that person's needs will escalate.

Challenging behaviour in response to needs not being met is very often a characteristic of this group and so plans that ensure a person's needs are met and therefore reducing the likelihood that behaviour will be triggered is paramount.

Planners working with people who require complex support particularly need to be able to take account of the relationship between disability related support needs and people's needs in mainstream service systems. By definition people who require complex support tend to have needs across multiple service systems and it is often inherently difficult to tease out what is a disability.

There is an established evidence base regarding positive behaviour support and planning frameworks for people who require complex support.

Specialised planning teams would be beneficial but drawing on external knowledge and expertise for planning would be beneficial. This expertise can be drawn from various places.

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The NDIA's practice guide for people who require intensive supports describe Regional Subject Matter Experts and an advisory team that would be consulted and would advise on plans for this group. A similar approach is used in the WA mode. But it would probably be more effective if there were dedicated planners who themselves had expertise and were connected to local experts outside of the Agency to consult and engage with.

The person themselves should also have access to some independent support as a safeguard.

Draft Finding 5.1

It is a false economy to have too few resources for Information Linkages and Capacity Building, particularly during the transition period when it is critical to have structures in place to ensure people with a disability are adequately connected with appropriate services.

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) supports this finding and argues that the absence of Information Linkages and Capacity Building puts people who require complex support at particular risk as they already face some of the greatest barriers to good planning. They are also at particular risk of not having appropriate services available.

Draft Recommendation 5.1

Funding for ILC should be increased to the full scheme amount for each year during the transition period.

The effectiveness of the ILC program in improving outcomes for people with disability and its impact on sustainability of the NDIS should be reviewed as part of COAG five-yearly review of scheme costs. ILC budget should be maintained at a minimum of \$131 million per annum until results from this review are available.

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) supports this recommendation if it should lead to specific strategies that will ensure that structures are in place that maximise the success of transition to the NDIS of people who require complex support.

Inclusion Australia (NCID) would call for any increased ILC to include specific strategies for supporting the transition of people who require complex support.

Draft Recommendation 5.2

The Australian, State and Territory Governments should make public their approach to providing continuity of support and the services they intend to provide to people beyond supports provided through the NDIS. These arrangements for services should be reflected in the upcoming bilateral agreements for the full scheme.

The NDIA should report, in its quarterly COAG Disability Reform Council report, on boundary issues as they are playing out on the ground, including identifying service gaps and actions to address barriers to accessing disability and mainstream services for people with disability

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) supports this recommendation. People who require complex support are especially likely to be accessing supports across multiple service systems, which all often struggle to meet their needs. Disability support systems are often the default response when other needs aren't met as a result.

Alternatively, an absence of quality and effective supports from mainstream or specialist disability services can also lead to an escalation of crisis in statutory systems such as justice and corrections and child protection.

To date there has not been any clear accountability mechanisms within jurisdictions to ensure that mainstream services meet their obligations. The funding of disability supports through the NDIA as a Commonwealth agency will mean there is an increasing focus on drawing a line around NDIS responsibilities vs mainstream system responsibilities that are largely the purview of State governments. But in the absence of clear accountability mechanisms and coordination to ensure access is followed through, there is a risk that either cost shifting to the NDIS will occur or that people will be left without a service.

Draft Recommendations 5.3

Each COAG Council that has responsibility for a service area that interfaces with the NDIS should have a standing item on its agenda to address the provision of those services and how they interface with NDIS services. This item should cover service gaps, duplications and other boundary issues.

Through the review points of National Agreements and National Partnership Agreements under the Federal Financial Relations Intergovernmental Agreement, parties should include specific commitments and reporting obligations consistent with the National Disability Strategy. The Agreements should be strengthened to include more details around how boundary issues are being dealt with, including practical examples.

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) supports this recommendation. There has never been a clear accountability mechanism to ensure that mainstream service systems, which are largely operated by State governments, have met their universal service obligations. Prior to the NDIS the resultant cost shifting to disability services was also borne by State governments. However, the introduction of the NDIS brings a new financial imperative to ensure that they do.

It was expected that the National Disability Strategy might be a vehicle to drive this sort of change, however that does not appear to have had any leverage.

As the ultimate mechanism for Commonwealth/State/Territory negotiations it would make sense to embed these issues within other Agreements so Ministers are then made directly accountable.

Draft Recommendation 6.1

The Australian Government should:

- *Immediately introduce an independent price monitor to review the transitional and efficient maximum prices for scheme supports set by the NDIA*
- *Transfer the NDIA's power to set price caps for scheme supports to an independent price regulator by no later than 1 July 2019*

Inclusion Australia (NCID) Response

Price setting mechanisms need to be sensitive to the particular market challenges of different kinds of supports reflecting the level of 'risk' to the person and the system of poor support. The price of support for someone who requires complex support is likely to be quite different to someone with straightforward personal care supports. People who require complex support require advanced practitioner support workers who skilled in positive behaviour support with sufficient maturity and experience and able to work independently in an individualised environment.

Given the challenges of working with people who require complex support, there can be a higher turnover of staff than

Inclusion Australia (NCID) recommends that there be examination of the reference packages used by the NDIA.

Given that this is a 'thin market' currently, the price to establish services to respond to this niche might be higher initially until they can be established.

Draft Finding 6.1

In a market based model for disability supports, thin markets will persist for some groups including some participants:

- *Living in outer regional, remote or very remote areas*
- *With complex, specialised or high intensity needs, or very challenging behaviours*
- *CALD backgrounds*
- *ATSI*
- *Acute and immediate needs*

In the absence of effective government intervention, such market failure is likely to result in greater shortages, less competition and poorer participant outcomes.

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) supports this finding and notes that for participants that cross multiple factors for thin–markets the challenge is even greater. For example, Aboriginal people with complex needs or very challenging behaviours who are living in regional, remote or very remote areas.

Inclusion Australia (NCID) is specifically concerned in our submission about thin-markets to support those people with complex needs or very challenging behaviours. We collectively describe this group as people who require complex support. We note that State and Territory disability support systems have already struggled to provide adequate and reliable services to this cohort, and that this ability to respond has been further exacerbated in regional and remote locations. Systemic responsiveness and sector capacity to support this cohort varies significantly across jurisdictions, and also within jurisdictions.

Where States and Territories have built up effective systemic responses for these cohorts, the rollout of the NDIS is in fact causing the dismantling of some of that sector capacity and thereby compromising rather than enhancing the market. For example the Australian Disability Justice Campaign, which includes several Inclusion Australia members, has reported to the Joint Parliamentary Standing Committee on the NDIS that existing service responses to people with intellectual disability in the criminal justice system in NSW as that State government is withdrawing funding from a range of services supporting people with disabilities to put that money in the NDIS bucket.

Participants in this cohort are some of the most vulnerable and at greatest risk where quality services that are responsive to their needs are not available.

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Inclusion Australia (NCID) believes that a dedicated transition strategy for people with complex support needs that includes specific sector capacity building in specialist disability supports as well as mainstream services is critical to respond to the very high risk of 'thin markets' for this group.

To respond to the risk of 'thin markets' for this group it is important to understand the particular challenges of supporting this cohort. People who require complex support rely on high quality services with a relatively high level of skills and expertise. It can be very challenging to recruit and sustain such staff, who at times working in very challenging environments. Quality services for this group often rely on more intense levels of support and supervision than exist for people with more straightforward needs.

These workforce challenges often have a significant implication for the price of services, and any work to respond to 'thin markets' for this group must ensure that the price is set at a level that will enable the right workers to be attracted, trained, supported and retained.

Information Request 6.1

In what circumstances are measures such as:

- *Cross-government collaboration*
- *Leveraging established community organisations*
- *Using hub and spoke (scaffolding) models*
- *Relying on other mainstream providers*

appropriate to meet the needs of participants in thin markets? What effects do each have on scheme costs and participant outcomes? Are there barriers to adopting these approaches?

Under what conditions should block-funding or direct commissioning of disability supports (including under 'provider of last resort' arrangements) occur in thin markets and how should these conditions be measured?

Are there any other measures to address thin markets?

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) would suggest that each of these measures would be appropriate, but that the utilisation of these and any other measures would need to be considered within a local context that responds to the pre-existing sector capacities. As we have indicated earlier, this pre-existing capacity for people with complex needs and challenging behaviour is not well developed or consistent across or within jurisdictions. When you layer this with additional factors such as regional or remoteness, or Aboriginal or CALD background then the interaction of localised factors and capacities becomes even more important.

For people who require complex support, cross-government collaboration is inherently necessary because by the very nature of complex support needs a participant often has needs across multiple domains and service systems. The capacity for cross-government collaboration will depend very much on capacity and policy settings of mainstream service systems and the disability sector. The interface principles between disability and other service systems and how they are negotiated within jurisdictions will also have implications.

Cross-government collaboration should reduce scheme costs and participant outcomes, but that is contingent on mainstream service systems taking responsibility for their service responsibility to this cohort and therefore their 'costs'. Barriers to these approaches will include the level of engagement of mainstream service systems and willingness to develop their capacity, and the political leadership shown by non-disability Ministers to ensure systems are responsive.

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Issues of budget implications and systemic capacity might be a barrier to these approaches, and they certainly have been in the past. Accountability via mechanisms such as COAG will be essential. High level systemic engagement complemented by localised operational engagement should assist in realising the opportunity for cross-government collaboration to respond to thin markets for this cohort.

Leveraging established community organisations to meet the needs of people who require complex support is essential. Utilising established community organisations is likely to result in lower up-front costs when compared to seeding new service organisations. Theoretically, utilising established community organisations should improve the sustainability of services and supports. However, before this can occur there needs to be clarity about the current capacity of established community organisations to respond to this cohort in order for it to be leveraged.

Inclusion Australia (NCID) reiterates that this has always been a cohort that pre-existing service systems have struggled to respond to and the level of capacity amongst established community organisations for this cohort is highly variable. Even where established organisations claim to have such capacity this needs to be tested. This includes testing whether established community organisations are using contemporary, evidence based principles and practices that are known to important to quality outcomes for this group.

Inclusion Australia (NCID) would be anxious to ensure that those organisations that can demonstrate their capacity to support this group well are sustainable, and this might mean a review of the reference packages and pricing to ensure that it is adequately responding to the needs of people who have complex support.

Inclusion Australia (NCID) contests that leveraging established community organisations will not be a sufficient strategy for responding to thin markets for people who require complex support and that there is a need for support for the development of niche services designed from the outset to be responsive to this group.

Direct commissioning and 'seed funding' on a block grant funding basis will be important to nurture new services. And depending on the work on pricing for this cohort, it might be find that some level of base funding complemented by individualised funding might need to be considered to ensure the sustainability of high quality and responsive services to this group given the risks to the participants and the scheme of market failure.

Hub and spoke or scaffolding models that allow expertise to be developed centrally and then shared into other organisations is also likely to be very appropriate for this cohort, and is an approached that has already been used in some jurisdictions.

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For example, the Western Australian government utilises a hub and spoke model to offer 'consultancy' type services from positive behaviour support specialists to disability service organisations as part of its positive behaviour support strategy. These approaches are particularly valuable for cohorts such as this where high levels of expertise are necessary but where disability service organisations might not necessarily specialise themselves.

It is also valuable in responding to regional service delivery where maintaining specialist capacity can be particularly challenging and service costs are often higher. Barriers to this approach might be knowing where to locate expertise for greatest effect. It is likely to be a relatively inexpensive response but would need to be complemented by a workforce development strategy to ensure that 'spoke' organisations were able to implement the recommendations of 'hub' experts.

It would not be a substitute for more comprehensive and direct interventions to improve market capacity, but would be useful support strategy especially for regional locations.

Relying on mainstream providers would not generally be an approach supported by Inclusion Australia. Mainstream providers have a poor track record in responding to this cohort, and disability services have always been the 'default' response when mainstream providers aren't responding.

This would unlikely have a positive impact for participants and poor interventions by mainstream providers would ultimately result in higher costs to the scheme. In regional, remote or very remote locations however where there is an inherent challenge in all service systems being able to respond and where disability service responses are at their thinnest, utilising established mainstream providers as a platform for localised responses might be a useful strategy.

This might be a context where localised capacity building within mainstream providers complemented by a 'hub and spoke' approach to provide ongoing expertise and support to mainstream providers in challenging locations might be effective.

Draft Recommendation 7.2

The NDIA should publish more detailed market position statements on an annual basis. These should include information on the number of committed supports, existing providers and previous actual expenditure by local government area.

The Australian Government should provide funding to the ABS to regularly collect and publish information on the qualifications, age, hours of work and incomes of those working in disability care roles, including allied health professionals.

Inclusion Australia (NCID) Response

Inclusion Australia potentially supports this recommendation, if the market position statements are useful in assessing performance on 'thin markets'.

Draft Recommendation 7.3

The NDIA's guidelines on paying informal carers who live at the same residence as a participant should be relaxed for core supports for the period of the NDIS transition. Such payments should be:

- *Accessible under clearly defined and public guidelines, which make reference to worker shortages in the relevant market using the NDIA's information about providers and supports in the participant's region*
- *Set at a single rate determined by the NDIS price regulator in a transparent manner*
- *Reviewed by the NDIA as part of plan reviews*

Inclusion Australia (NCID) Response

Inclusion Australia supports this recommendation where it has been demonstrated that this is a last resort, and notes that this might need to extend beyond the transition period, particularly in the case of 'thin markets'.

Where the presence of a 'thin market' means that participants find it difficult to access appropriate and consistent services informal carers can be left without any formal support at all. In the absence of formal, funded supports payment to informal carers is appropriate and also provides compensation for the lost opportunity of paid employment.

Information Request 7.2

How has the introduction of the NDIS affected the supply and demand for respite services? Are there policy changes that should be made to allow for more effective provision of respite services, and how would these affect the net costs of the scheme and net costs to the community?

Inclusion Australia (NCID) Response

The capacity for informal and family carers to provide informal support to their family members with a disability is essential to the long-term sustainability of the scheme. The sustainability of informal care is critically impacted by the health and well-being of family carers. Critical to this is the opportunity for informal carers to have a break from caring responsibilities so they can focus on their own health and wellbeing or participate in paid employment, maintain relationships with the person they care for separate to their explicit additional caring responsibilities, and also have the opportunity to respond to the caring needs of other people in their family and community.

For people who require complex support, informal support is already under increased pressure because of the impacts of challenging behaviour, or because of socioeconomic, health or other challenges impacting on the person and their informal carers. Because the costs to the scheme are greater for people who require complex supports already, the risk to the scheme of informal care not being sustainable is even greater.

'Respite' services have historically been the mechanism through which informal carers accessed support that would give them a break from caring responsibilities. 'Respite' has for some time been a contested term that has often caused division between people with disabilities and families and carers, with critics arguing that it constructs informal care of people with a disability as a 'burden'. 'Respite' services have long been criticised as meeting the needs of carers while not meeting the needs and goals of a person with a disability.

Inclusion Australia (NCID) supports the explicit and specific focus of the NDIS on the needs of people with disability, however many informal carers have reported to Inclusion Australia members that NDIS planning processes make it difficult for them to articulate what support they need in their to allow them to meet the needs of their family member.

Draft Recommendation 8.1

The NDIA should implement the eMarketPlace discussed in the integrated Market Sector and Workforce Strategy as a matter of priority.

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) supports this recommendation, if the eMarketPlace enables a focus on responding to 'thin markets'.

Information Request 8.2

Is there scope for Disability Support Organisations and private intermediaries to play a role in supporting participants? If so, how? How would their role compare to Local Area Coordinators and other support coordinators?

Are there any barriers to entry for intermediaries? Should intermediaries be able to provide supports when they also manage a participant's plan? Are there sufficient safeguards for the operation of intermediaries to protect

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) is the national peak body for intellectual disability. We are a federated body with an agency member from each State, and those agency members are the leading advocacy and consumer organisations for people with intellectual disability and their families and carers in their state.

Inclusion Australia (NCID) believes that there is substantial scope for Disability Support Organisations, and specifically consumer and advocacy organisations, to support participants to prepare for and navigate the scheme. These organisations already have well established grass roots connections to people with disability and their families and carers. They have trusted reputations amongst people with disabilities and families and carers and are recognised and trusted as independent organisations whose focus is specifically on the person and their families and carers with no vested interest as an agent of the system or as a service provider. This distinguishes them from Local Area Coordinators who are often seen as agents of the system, and which don't have the established reputations and profiles and independence of DSOs.

Inclusion Australia (NCID) would strongly advocate for vibrant and independent Disability Support Organisations – particularly consumer and advocacy organisations – are a critical part of the foundational infrastructure that is required to support the success of the NDIS.

(Response continued on next page)



Inclusion Australia (NCID) believes that the opportunity for Disability Support Organisations to play a role should be prioritised over the introduction of private intermediaries. Disability Support Organisations are well established, have extensive experience in supporting people with disabilities and families and carers to navigate systems.

Most importantly they have high levels of trust amongst people with disabilities and their families and carers and existing well developed networks within community, and a demonstrated capacity to continually expand their reach and engagement in a cost effective way.

Draft Recommendation 9.4

The performance of the NDIS should be monitored and reported on by the NDIA with improved and comprehensive output and outcome performance indicators that directly measure performance against the scheme's objectives.

The NDIA should continue to develop and expand its performance reporting, particularly on outcomes and Local Area Coordination and ILC activities. The NDIA should also fill gaps in its performance reporting, including reporting on plan quality (such as participant satisfaction with the plans and their planning experience, plans completed by phone versus face-to-face, and plan reviews).

Inclusion Australia (NCID) Response

Inclusion Australia (NCID) supports any recommendation to ensure that there is transparent and robust evidence about the performance of the NDIS. This should include information that assists all stakeholders to monitor the performance of the NDIS on key population groups of participants.

Inclusion Australia (NCID) believes that there should be a focus on monitoring the performance of the NDIS for participants who face the greatest risk of poor outcomes under the NDIS, including people who require complex support and other participants in 'thin' markets.

Inclusion Australia (NCID) supports performance reporting for LAC and ILC activities.

Inclusion Australia (NCID) supports an explicit focus on performance reporting on plan quality with a specific focus on participant feedback. Inclusion Australia would also recommend that assessments of plan quality also measure the quality of plans in terms of their alignment with established best practice and evidence for particular cohorts. For example, the quality of plans for people who require complex support should be assessed against the principles and evidence regarding positive behaviour support.

Information Request 9.1

The Commission is seeking feedback on the most effective way to operationalise slowing down the rollout of the NDIS in the event it is required. Possible options include:

- *Prioritising potential participants with more urgent and complex needs*
- *Delaying transition in some areas*
- *An across-the-board slowdown in the rate that participants are added to the scheme.*

The Commission is also seeking feedback on the implications of slowing down the rollout.

Inclusion Australia (NCID) Response

As indicated earlier, Inclusion Australia (NCID) doesn't support slowing down the rollout. However, if such a course is taken then we would recommend that potential participants with more urgent and complex needs be prioritised and that this was supported by a longer period of joint responsibility between the Commonwealth and the states for a designated period to ensure a safety net so people aren't left without supports during transition.