Report to the Independent Advisory Council of the National Disability Insurance Scheme

Activating capacity building in the NDIS at surge and at full Scheme roll out

April 2017

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Introduction

The insurance principles underpinning the NDIS require significant effort directed at building capacity to reduce the need for long-term care and support. This increased capacity will be seen in people with disability (not just participants) becoming more active citizens: more engaged economically and socially, more included in their communities and more self reliant. Active citizenship is critical for the Scheme as well as the participants because active citizens are more resilient, develop support options that are more enduring and build ordinary lives strengthened by relationships, not just services.

Some people with disability are already engaged in their community and leading ordinary lives. For others, capacity building will be crucial requiring concerted action in four areas: a) skill building of the participant, b) the identification and strengthening of informal support in all areas of a participant's life, thereby embedding the participant in his/her community, c) the use of services that understand their role as promoting independence and facilitating relationships and d) avenues for emotional and practical assistance on the journey.

A guide is an important ingredient in activating capacity building and holding these areas together, especially where many are currently fragile. The work of the guide is relationship-based work: it starts with the development of trust, by the participant and their family, carers and support network. It proceeds with high expectations, a vision of possibilities and a solution focused approach. The work takes time.

Whilst for the NDIS, the aim of the First Plan is to transition participants into the Scheme, the expectations of many participants, created by the NDIA and state based information and pre-planning resources, is to use reasonable and necessary support to begin a journey toward meeting one's goals and aspirations. The assistance of a Local Area Coordinator or the allocation of Support Coordination are important NDIS strategies to guide participants toward the capacity building required to meet goals and aspirations and reduce the need for long term care and support.

Acknowledging the significant constraints faced by the NDIS in its transition environment, the purpose of this paper is review the NDIS strategies to activate capacity building so as to give consistent messages that positive outcomes for participants (built on increased independence and inclusion) are consistent with the sustainability of the Scheme. To this end, the paper will open with observations about the value and contribution of capacity building to participants and the Scheme. It will then review the role, strengths and challenges of Local Area Coordination, Support Coordination and peer networks to propose approaches best suited to activate capacity building at surge and at full scheme roll out.

The impact of capacity building on people with disability and families

State and Territory provision	NDIS without capacity building	NDIS with capacity building
People **maximise their deficits** in an effort to get maximise resources allocated to them.	People continue to maximise their deficits in order to maximise their resources	People know that positive lives are built on high expectations. An overstatement of deficit and need is incompatible with high expectations.
People **are frightened to use their initiative** lest it reduces their eligibility or priority for government funded services and supports.	People lack examples of the type of initiative that can lead to positive outcomes People do not know how to help people with disability to develop informal support (relationships with people who are not paid).	People have ideas and develop confidence. They understand that paid support contributes to positive lives but that an excess of paid support can drive out freely given relationships that are central to a meaningful life.
People with disability **defer to others as the experts** on their lives.	People create plans that continue to defer to service providers as the centre of expertise.	People have confidence to negotiate what they want and how they want it. They exercise choice and take the level of control they feel comfortable with.
People have **service plans.**	Case managers from services assist people to go through the motion of planning, but limit their thinking and planning to the current disability system. A key focus of planning is to get as much as you can from NDIS.	People develop goals for the life they want to live and develop plans to enable the use NDIS resources to complement the support provided by family and friends.
Funding is allocated to services that provide assistance to the most needy.	Funding is used to purchase services from traditional disability service providers.	People are actively choosing from a range of services and supports including mainstream and informal supports. The NDIS package assists people to build informal support.
People are dependent users	People are consumers of	People are active citizens,

State and Territory provision	NDIS without capacity building	NDIS with capacity building
of service.	service who have some choice but limited opportunity to avail themselves of the choice and control anticipated in the NDIS.	exercising choice and control, engaging in social, economic and political life.

In state and territory service systems, the majority of people with disability, particularly those with intellectual disability spend their lives with other people with disability in services that provide little choice and no control. Participants are clients. At the point of entry, families have described their family member in negative, deficit language in order to maximise their allocation of funding. They have selected the service mainly on the basis of vacancy, geography and hours of operation and a planning meeting has enabled them to choose from the limited menu of service offerings. The person spends the very vast majority of time in a group.

The NDIS certainly provides an opportunity for something different. The challenge is however, that most people have no experience of choice and control. Some people have had no experience in making significant life decisions and their families are exhausted from a lifetime of battling the service system. Others have bigger dreams but no idea how to move from a life of services to the life they want.

The key to unlocking opportunities for people with disability and families is investment in capacity building. Service workers will come and go but people with disability and their families will be there in the long run and so investment in their capacities represents investment in a sustainable future. Insurance principles dictate that this investment in participants translates into a reduction in the quantum of core supports a participant requires. Participants from the rationed state systems will need to build confidence that reducing core supports is a positive citizen enhancing strategy and that additional support will be available at a future time if it is needed. This type of discussion is best facilitated in the context of a trusting relationship.

Local Area Coordination, Support Coordination and peer networks are three current levers in the NDIS to activate capacity building. The opportunities and challenges of each are discussed below.

Local Area Coordination

Role

Material on the NDIS website describes Local Area Coordination as a 'changing role'[1]. *The Local Area Coordinators in undertaking their services will vary their focus and effort on specific activities depending on the status of readiness and the agreements between State, Territory and Commonwealth governments to deliver the NDIS.*

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[1]   https://www.ndis.gov.au/html/sites/default/files/LAC-role-partners.docx

Practice guidance[2] defines the primary role of a Local Area Coordinator is to:

- *support implementation of all supports in the plan, including informal, mainstream and community as well as funded supports*
- *coordinate assessments, reports and services proposals*
- *capture any required data for the Agency*
- *identify strategies and solutions for managing risks such as ageing carer, sustaining informal supports, sustainability of housing*
- *support the participant through identifying and selecting providers, monitoring plan outcomes and plan expenditure*
- *strengthen and enhance participant's abilities to self-direct their own supports*
- *provide the NDIA with reports on outcomes and success indicators within the agreed reporting frequency*
- *build the skills and resilience of the participant to participate in social and economic life.*

Strengths

Local Area Coordination is widely available and has a positive and empowering reputation of facilitating inclusion that was built on experience in Western Australia[3]. Many of the state based iterations of LAC have been less effective because of the way in which the role has been conceptualised and operationalized.

Challenges

For the 80% of participants in the General and Supported streams at surge, the LAC role is primarily one of planning and plan implementation. Different to the positively evaluated LAC model of WA, the NDIS LAC role has significant responsibility for NDIS processes and hence may lack the level and duration of engagement necessary to be a positive disruptor of lifestyles built on client-hood and dependence. The requirements relating to planning and plan implementation reduce the opportunity for the LAC to provide a positive influence that changes the appetite for capacity building and a different life style.

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[2] *Practice Guidance, Plan Implementation and Monitoring, Guidance for planners, LACs and delegates* v1.01

[3] Disability Service Commission, (2003) Review of Local Area Coordination Program Western Australia, access at http://www.derby.gov.uk/media/derbycitycouncil/contentassets/documents/adultsocialcare/WesternAustraliaGorvernment-Review-of-Local-Area-Coordination.pdf. P iv *A review of 17 previous studies of LAC concluded that LAC was "a success story" with positives far outweighing negatives, and that previous positive evaluations can be regarded as "continuous, enduring, long term and consistent over time."*

Support Coordination

Role

Practice Guidance[4] describes Support Coordination as a capacity building support that provides:

"Assistance to strengthen participant's abilities to coordinate and implement supports and participate more full in the community. It can include:

- *initial assistance with inking participants with the right providers to meet their needs*
- *assistance to source providers*
- *coordinating a range of supports both funded and mainstream and build on informal supports*
- *resolving points of crisis*
- *parenting training; and*
- *developing participants resilience in their own network and community*
- *developing participant capacity for social and economic participation*
- *managing expectations of reasonable and necessary funded supports.*

Strengths

The recognition that vulnerable participants need a skilled guide to assist them to implement their plan and build their capacity is a strength and critical for the sustainability of the Scheme.

Challenges

Role and time frame

The IAC has taken a consistent view that the capacity building elements of Support Coordination need to be strengthened and that the level and duration of its allocation needs to match the outcomes sought[5].

Practice guidance stipulates two limiting elements that potentially impact on its potency. Firstly, Support Coordination is only allocated to participants in the intensive and super intensive streams, almost all of whom, by definition, lack effective informal support. Secondly, that Support Coordination is a time limited[6] intervention.

People who lack effective informal support need guidance over a significant period of time to positively disrupt patterns that do not contribute to positive outcomes of increased independence and participation. The time limited nature of Support Coordination means

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[4] *Practice Guidance, Plan Implementation and Monitoring, Guidance for planners, LACs and delegates* v1.01

[5] *IAC "Support Coordination as a tool for capacity building in the NDIS"* May 2016 and August 2016

[6] Practice Guidance, p12 *"There is an expectation that, where possible, Support Coordination will be replaced in subsequent (review) plans by Support Connection or Local Area Coordination.''* The document emphasises this point in bold.

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that in practice, only the case management elements are implemented and there is little or no attention to the capacity building tasks that are central to reducing the long-term need for support. These tasks include work to:

- build informal support
- embed (not just connect) the participant to the community in meaningful ways that build belonging
- guide and mentor services to work toward participant goals of increased independence and relationships
- identify areas for next steps, and
- support the participant and his/her newly connected informal support to speak up.

The time limited provision of Support Coordination makes assumptions about the availability of providers of core supports that are skilled at working in the developmental mode identified above. In an ideal world, competent services are readily available to undertake this work but anecdotal evidence suggests that the reality is very different, to the detriment of the participant and the Scheme. Elsewhere, the IDRG[7] has called for a market scan to test the readiness of providers of core supports to assist participants in ways that facilitate increased independence including identifying the core competencies required for support workers to increase participant independence.

Generalist nature

Support Coordination is not differentiated by type of need or participant so it is often provided by Support Coordinators without specialist experience in working with the targeted cohort.

Specialist expertise is critical for more effective and efficient provision. The IDRG, for example, has expressed a preference for specialist teams of planners having seen practice across trial sites for people on the margins in touch with criminal justice, mental health and drug and alcohol systems. Similarly, where Support Coordinators have knowledge, skills and experience in working with specific groups or on specific issues, their potency is increased.

The effectiveness of Support Coordination would be enhanced by the development of targeted Support Coordinator roles to work with identified groups such as participants:

- in touch with the criminal justice system
- who are eligible for SDA
- with complex behaviour
- with complex health
- who have informal support but face complex situations such as significant barriers to living in their own home, having a job or valued social role, belonging in community. The IAC paper *Enhancing self-direction and self-management in the NDIS* refers to this assistance as 'lifestyle development assistance'.

Targeted Support Coordination as identified above would enable effective provision if

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[7] IDRG *"NDIS Supports for independence,* December 2016

coupled with identified knowledge, skill and experience requirements reflected in a separate registration process.

Target group

The target group for Support Coordination may be unnecessarily restricted.

The final group identified above highlights a group that is most keen to increase their capacity to live an ordinary life but need guided skilled assistance to do so. These tend to be participants with significant disability who have traditionally been subjected to low expectations with a natural pathway to grouped accommodation and day programs. Many people with these profiles are supported by engaged families who seek guidance as to how to build ordinary lives for their family member with disability.

The now obsolete Support Coordination Framework allocated Support Coordination according to a matrix of capacity of participant AND complexity of plan. This enabled the provision of Support Coordination for people with significant disability who want to avoid congregate services and want paid staff to facilitate relationships and help them be more independent. The goals of an ordinary home with a combination of paid and informal support and a real job in open employment assisted by informal support developed in the workplace, require highly complex planning, negotiation and coaching. The Support Coordination Framework enabled the allocation of Support Coordination to plan and implement the highly nuanced steps required to succeed. Evidence from state and territory systems suggests that assistance of this nature represents value for money contributing to participants being more independent, more safeguarded, with greater levels of participation and less need for paid support.

The need for expert guidance even where a person with disability is supported by competent family is evidenced in the link below where skilled planning and skill development enabled a man with intellectual disability and autism to live in his own home with paid support to compliment the informal support provided by family and friends. https://adammovesout.wordpress.com/background/. Adam's NSW support package is less than half the resources that would be allocated for his support in a group home. Expert guidance of a type that should be provided under Support Coordination was pivotal in assisting this man and his family develop such a full and valued life. The capacity building investment paid off with significantly reduced need for long-term care and support.

Registration requirements

Elsewhere[8], the IAC and the IDRG have argued that registration for Support Coordination or any of the areas under the Assist Life Stages Transition Cluster do not require evidence of the knowledge, skills and experience required to provide the capacity building support. In fact, many providers offering Support Coordination advertise the services as case

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[8] IAC, *(*May 2016) *Support Coordination as a tool of capacity building in the NDIS*
IAC (August 2016) *Support Coordination as a tool of capacity building in the NDIS: A discussion paper*
IDRG (June 2016) *Requirements of support coordination to meet the goals of the NDIS for people with intellectual disability*

management on their websites.

If the NDIS is to achieve the potency required of the role, more rigorous requirements in the registration process are required.

Incongruity with Agency response to IAC and IDRG recommendations

The Agency has indicated that Support Coordination is the capacity building response to critical issues identified by the IAC and IDRG such as support for decision making, support to build personal safeguards and 'technical assistance'[9] to direct one's own support. These elements were extremely weak in the Support Coordination Framework and are not identified in the current Practice Guidance.

If Support Coordination is not the Agency response to these pressing needs, the Agency needs to identify and implement an appropriate response.

Conflict of interest

There are mixed views in the IAC over the pros and cons of requiring a separation of provider of Support Coordination from provider of core supports. In the context of more entrants into the Support Coordination market, further work is required explore whether separation has an impact on outcomes for participants.

Peer networks

Role

In the context of the NDIS, the role of peer networks for people with disability and families is to facilitate mutual support in local communities as a strategy to build capacity to exercise choice and control, engage with the NDIS and other community supports as well as actively participate economically and socially.

Strengths

Peer networks are a low cost capacity building strategy reviewed by the IAC in its 2015 paper, *Capacity building for people with disability, their families and carers'.*

The paper's review of literature concluded that there is

"… a general consensus that engagement with a support group improves the health and wellbeing of members both directly and indirectly. The direct impact is seen through encouraging social integration, fostering self esteem, positive emotion, reducing social isolation and enabling group members to give back to others (Families4Families 2014). The indirect impact is experienced because support groups act as a protection against stressors and build coping skills. Their effectiveness arises because they provide opportunities for vicarious learning (learning through observing others and the impact of outcomes of their behaviours) and vicarious learning improves self-efficacy. Support groups can promote

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[9] The term 'technical assistance' has been further clarified as 'lifestyle development assistance'

behaviour change by enabling group members to gain increased insight into their problems and as a result develop increased confidence.

Many studies demonstrate that peer support groups are also successful in facilitating the achievement of a non social goal such as mapping resources in a community, reducing rate of re-offending and increasing the rate of breastfeeding."

Two of the keys to success of peer networks are the continuity of support over time and the availability of a moderating organisation to keep the group on track.

Challenges

Most people with disability across Australia do not have access to peer networks. At the end of 2014, the NDIS funded the Disability Support Organisations project allocating 19 contracts to 18 organisations requiring each to develop up to 20 peer networks.

The project evaluation that demonstrates the positive capacity building impacts of the networks was submitted to DSS in January 2017. In the meantime however, the project funding runs out in June 2017 leaving a gap of up to 2 years until possible new funding through the ILC. Even without the gap in time, the limited funds and the significant charter and aspirations of the ILC make it unlikely that the ILC will deliver a national network of local peer groups.

Participant motivation

The appetite of the participant to work toward increased independence, social and economic participation and increased inclusion is a critical factor that NDIS processes must take into account. Within all streams, there will be participants and their families who are very keen to engage and change their lifestyle and there will be participants and their families whose goal is for everything to remain the same.

This paper proposes that for participants who are motivated and eager to build capacity, immediate resources should be placed in their first plan to demonstrate that the NDIS is committed to supporting participants be as independent and as contributing as they can possibly be. At surge, more reluctant participants should transition into the Scheme, maintaining current supports with Agency commitment to take a more concerted approach to motivate an appetite for capacity building following full Scheme roll out.

The way forward

What does this mean for activating capacity at surge and at full scheme?

The review of current NDIS levers to activate capacity building suggests that LACs do not have the time or relationship to do more than include capacity building items in the plans of motivated participants. They are unlikely to be able to change the appetite of participants and their families for change. Support Coordination on the other hand provides more time and possibility for engagement but its generalist nature and the fact that it is not allocated to some very motivated participants who need guidance suggests that it not applied in the

most effective ways. Finally peer networks provide low cost capacity building over an extended period of time but are not available to most participants because there are limited local peer networks across Australia.

The recommendations below seek to maximise the opportunities for capacity building of NDIS participants:

Recommendations at surge

Identify what works to inform future practice

1. Commission research into the competencies required to:
    a. activate and guide the development of capacity in participants in different cohorts across the lifespan
    b. positively disrupt patterns of service provision that do not lead to increased independence and social and economic participation
    c. map the competencies across elements of the SDOM, Support Catalogue and ILC
2. Commission a market scan to test the availability of providers that have the competencies identified in the research.

Communicate clearly about the capacity building tools of the NDIS

3. Develop a Practice Guide in relation to capacity building of participants in different cohorts across the lifespan
4. Amend Plan Implementation Practice Guide to allocate Support Coordination in relation to the complexity of the goal, not just the circumstance of the participant
5. Develop an NDIS item of 'Lifestyle development assistance' in the Support Catalogue. This is a Support Coordination type function that guides participants who want to increase self-direction and maximise independence and inclusion. The focus of ''Lifestyle development assistance' would include:
    o facilitating relationships
    o building informal support
    o building valued roles
    o guiding informal supporters to direct staff in undertaking these roles.

Improve effectiveness of Support Coordination

6. Develop targeted Support Coordination roles to work with identified groups such as participants:
    - in touch with the criminal justice system
    - who are eligible for SDA
    - with complex behaviour
    - with complex health
    - who have informal support but face complex situations such as face significant barriers to living in their own home, having a job or valued social role, belonging in community (i.e. 'lifestyle development assistance').

7. Change registration requirements for Support Coordination to reflect appropriate knowledge, skills and experience.

Provide capacity building supports for participants motivated and ready to actively engage

8. Allocate specialist support coordination and other capacity building supports for participants who are ready and seek active assistance to be more independent, more engaged and more included.

Fund peer networks as a long term cost effective capacity building strategy

9. Develop a national network of peer support groups.

Recommendations at full scheme

10. Amend SDOM in line with research about what works.
11. Investigate the impact of separation of Coordination of Support from core supports has on outcomes for participants.
12. Develop a strategy to activate and guide the development of capacity of participants and positively disrupt patterns of service provision that do not lead to increased independence and social and economic participation.