

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

Support Co-ordination and the sustainability of the NDIS

November 2016

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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 requires 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 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.

In Western Australia for many years, this role was played by Local Area Coordinators (LAC) who were transformative in the lives of people with disability¹. 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.

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 allocation of Support Coordination is an important NDIS strategy 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 to identify issues that require investigation in relation to the current conceptualisation and implementation of Support Coordination.

Whilst some participants have benefited from current implementation, some concerns stem from anecdotal observations of participants and people who work with participants relating to the operationalization of the recent *Practice Guidance*:

¹ Disability Service Commission, (2003) Review of Local Area Coordination Program Western Australia, access at <http://www.derby.gov.uk/media/derbycitycouncil/contentassets/documents/adultsocialcare/WesternAustraliaGovernment-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."*

Plan Implementation and Monitoring: Guidance for Planners, LACs and Delegates (Practice Guidance) which has replaced the Support Coordination Framework. Additional data is required to explore the extent and impact of concerns, the heart of which is whether Support Coordination as currently conceived misses critical opportunities to activate capacity building, necessary for reduction in the long term need for care and support.

Challenges to the effectiveness of Support Coordination

The way in which Support Coordination is conceived and implemented may reduce its potency

Concerns about the current conceptualisation and implementation of Support Coordination relate to:

- the extent of its capacity building
- whether the level and duration of its allocation are sufficient
- whether the target group is unnecessarily restricted

The Practice Guidance definition of Support Coordination outlines plan implementation and capacity building elements. Experience suggests however that for the majority of participants activation of the First Plan and resolution of crises take all the hours allocated.

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 allocation needs to match the outcomes sought². This is in order to provide earliest and maximum effort to build capacity to reduce the long-term need for support.

The Practice Guidance stresses the time limited nature of Support Coordination³ and this may limit its ability to be the needed guide in the areas that are so central to reducing the long-term need for support: i.e.

- in strengthening informal support at home, at work, in leisure activities, activities that are central to embedding the participant in his/her community.
- guiding and mentoring services to work toward participant goals of increased independence and relationships (work in which they are not experienced),
- identifying areas for next steps, and
- supporting the participant and his/her family to take more initiative and speak up.

²IAC “Support Coordination as a tool for capacity building in the NDIS” May 2016 and August 2016

³ 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.

In an ideal world, competent services are readily available to undertake this work but the reality is that very few services currently work in this way and this is to the detriment of the participant and the Scheme.

The IAC acknowledges that Support Coordination is an expensive NDIS service and hence strategies to target its use very tightly are understandable. The concern however is that the sunset clause may limit aspirations for participants because the goals of increased independence and social and economic participation usually require capacity building in a trusted relationship over time frames of more than one plan. The availability of goal focused Support Coordination beyond one plan is usually required to move from dependent client-hood to active citizenship, enhance independence, strengthen informal support and reduce the long term need for support.

The target group for Support Coordination may be unnecessarily restricted. The Practice Guidance indicates that Support Coordination is only for participants in the intensive and super intensive streams and this prevents participants with significant disability who have informal support (and hence fall into the general or supported stream) from expert guidance⁴ they seek to move toward an ordinary life, included in the community.

Local Area Coordinators assist participants in the general and supported streams to implement their plans. The fact that this is a *'non ongoing service'*⁵, and has an expectation *"that participants will gain skills to participate in NDIA processes and gain independence in creating and maintaining supports"*⁶ means that it fails to provide the expert guidance many participants need to move away from congregate programs toward an ordinary life included in the community.

LAC support has had variable impact. Whilst a senior Agency staff member reports that some family members have returned to work, other families have reported the dreadful dilemma of placing their family member in a congregate program or reducing their hours of work as a result of their transition to the NDIS. A number of NSW families have been devastated by the lack of allocation of Support Coordination which they had been led to believe would provide the 'technical assistance' they previously experienced through shared management.

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 wanted to avoid congregate services and want paid staff to facilitate relationships

⁴ This is referred to as 'technical assistance' in the IAC paper (2016) *Enhancing self-direction and self-management*

⁵ Practice Guidance p9

⁶ Practice Guidance p9

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 supported 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.

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.

The discussion in relation to whether Support Coordination is appropriately conceptualised and implemented to maximise participant capacity would be enriched in the context of evidence and further analysis in relation to:

- Whether the provision of Support Coordination (taking into account level and duration) makes a difference to a person living in their own home, having a job, being an active member of the community
- The relationship between the existence of informal support and the need for Support Coordination
- The relationship between the provision of Support Coordination and the reduction in need for long term care and support
- The identification of the profile of participants and families who could benefit from Support Coordination.

Availability of providers who support participants in capacity building ways

The Practice Guidance assumes the availability of providers who support participants in capacity building ways that promote independence and reduce the need for future reasonable and necessary support. This may not be the case.

Elsewhere, the IDR⁷ has argued that services do not see their role as promoting independence and their workers do not have the knowledge, skills, experience and motivation to do so. Support Coordination was identified as a critical strategy to increase the likelihood that services would assist participant in capacity building

⁷ Intellectual Disability Reference Group (2016), *Support for Independence*

ways by assisting them to negotiate appropriate service agreements, monitor progress and guide steps to increased independence.

Questions about the prevalence of providers who support participants in capacity building ways requires inquiry as to:

- Whether providers of core supports perceive their role as assisting participants to facilitate relationships and be independent
- Whether support workers have the knowledge, skills and competence to facilitate relationships and support participants to be more independent.

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 issues such as support for decision making, support to build personal safeguards and 'technical assistance' 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.

Generalist nature of Support Coordination

Support Coordination is not differentiated by type of need or participant so it is often provided by Support Coordinators with little or no experience in working with the targeted cohort.

Specialist expertise is required to assist participants in more effective and efficient ways. 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 specialist⁸ Support Coordinator roles to work with identified groups such as participants:

- in touch with the criminal justice system

⁸ Practice Guidance identifies Specialist Support Coordination as a time limited, case management intervention necessitated by specific high level risks in the participant's situation with a focus on removing barriers and reducing complexity. Specialist Support Coordination in Practice Guidance is paid at a higher rate. Reference in this paper to 'specialist Support Coordination' is NOT of this nature and refers to work with identified target groups for which specialised knowledge, skills and experience are important..

- who are eligible for SDA
- with complex behaviour
- with complex health
- who have informal support and face significant barriers to living in their own home, having a job or valued social role, belonging in community

Specialist Support Coordination as identified above would enable effective provision if coupled with identified knowledge, skill and experience requirements reflected in a separate registration process.

Skill base of Support Coordination and its registration

Elsewhere⁹, 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 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.

Conflict of interest

The separation of Support Coordination from provision of core supports provides vulnerable participants, many of whom are in closed systems, with an independent person who can assist them to see new possibilities.

Whilst the IAC acknowledges the thin market, it believes that current practice that allows, for example, a group home provider to also provide Support Coordination to the same participant, removes the safeguard and the opportunity facilitated by an independent third person.

It is critical that Market and Sector take steps to stimulate the market to achieve more choice of providers of Support Coordination with requisite knowledge and skills. Priority should be given to tightening the conflict of interest provision once there are sufficient providers in the market.

Conclusion and recommendations

The IAC understands the enormous constraints of surge but is concerned that

⁹ 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*

Support Coordination as currently conceived misses critical opportunities to activate capacity building, necessary for reduction in the long-term need for care and support. The IAC believes that adjustments related to the recommendations below are consistent with insurance principles and hence strengthen the sustainability of the Scheme.

Recommendations

Immediate

That the Agency:

1. Strengthens the capacity building elements of Support Coordination and allocates Support Coordination at a level and duration commensurate with the outcomes sought
2. Identifies additional target groups who would benefit from Support Coordination with particular consideration given to participants in life stage transition and participants who face significant barriers to ordinary life goals such as living in one's own home, having a job and belonging
3. Extends the market of appropriately skilled providers of Support Coordination by:
 - a. identifying the skill base required for effective Support Coordination
 - b. changing the registration requirements to reflect the requisite skill base
 - c. Identifying specialist Support Coordination roles to reflect work with target populations including participants:
 - i. in touch with the criminal justice system
 - ii. who are eligible for SDA
 - iii. with complex behaviour
 - iv. with complex health
 - v. who have informal support and face significant barriers to ordinary life goals
 - d. taking steps to stimulate this market to ensure greater choice of Support Coordination providers

Medium term

That the Agency:

4. Undertakes research related to the questions posed in this paper
5. Identifies the Agency response to support for decision making and support to build personal safeguards

6. Strengthens the conflict of interest provision to ensure that a provider of core supports cannot also provide Support Coordination for the same participant.