



## **NDIS External Consultation Support Coordination Discussion Paper 2020**

### **Background: WA's Individualised Services (WAI S)**

Western Australia's Individualised Services (WAI S) is a member-based community organisation working in partnership with people, families, service providers and government agencies to promote and advance individualised, self-directed supports and services for people living with disability, including psychosocial disability.

Since our inception in 2010, we have evolved to become thought leaders in this space, providing comprehensive, intentional support with integrity, passion and authenticity at our core. By leveraging our extensive local, state, and international network, we seek to lead, influence, innovate and inform to create meaningful and lasting change, supporting people to build capacity and live their lives on their own terms.

WAI S has a specific focus and purview of supporting and developing the capacity of people, families, service providers, Local Co-ordinators and government, specifically in the area of individualised, self-directed supports and services.

WAI S appreciates the opportunity to provide a submission in response to the NDIA's Support Coordination discussion paper. We acknowledge that support coordination is a relatively new support to people. We hope this is an opportunity to ensure that improvements can be made so that it becomes a service of real benefit to people and families who choose to have a support coordinator.

### **Inclusion of Support Coordination (SC)**

#### **What factors should be considered when determining if, when and for how long support coordination should be funded?**

- There is no consistent approach in determining if support coordination should be allocated and how much support coordination is considered reasonable and necessary.
  - Allocation of Support Co-ordination:
    - It is not consistent and there are no 'reasons' or clarity provided to people and their families regarding why they do or do not get SC in their plan. Sometimes, people are allocated a SC and told it is 'mandatory' they have one (but they believe they don't want or need one), and some people are not



allocated a Support Co-ordinator (when they believe they do 'want and need one).

For example, a family speaking quite a unique dialect of a language, isolated without outside social or organisational connections, with a lack of understanding of what supports are available, and with evidence provided to the NDIS of the need for support coordination, were not provided support coordination, even though they identified that this would assist them greatly in implementing their plan.

- There is a significant gap in the system in understanding complexity, vulnerability and risk:
  - The NDIS needs to develop a better depth of understanding of the people who may benefit from support coordination and WHY. This includes people who are Culturally and Linguistically Diverse (CaLD), Aboriginal and Torres Strait Islander (ATSI) peoples, people with complex communication access needs, people who are socially isolated and people who have a history of trauma where trust is required to be built. People whose communication and processing style means that much more time is required than another person might need to process information and come to a decision are not being given due consideration in the allocation of SC and/or hours.
  
- The NDIS, as a system can be difficult to navigate, understand and to communicate with. There is a lack of acknowledgment that the need for support coordination may stem, not just from capability/ capacity building and vulnerability/risk, but simply to navigate the system itself, the language and acronyms used etc.
  
- Support coordination could be offered to all people with first plans, including people who have chosen to self-manage. Importantly noting that any suggestions as to whom should be offered support coordination should not be interpreted as support coordination becoming mandatory. It is an offer of support for people to accept, if they determine it will be more helpful than not.



- Hours of Support Co-ordination:

- Support Co-ordination needs to be adequately funded in peoples plans to be effective, otherwise it becomes a waste of NDIS funds that does not achieve the outcomes it is intended to create.

For example, people and their families are being told they have to access SC so there is 'evidence' and a report to assist with determining reasonable and necessary supports. This is despite the person and their family accessing allied health professionals for reports for this purpose. This is a pointless exercise and a waste of NDIS funding in the context of reports already being carried out. This is also an example of people being told support coordination is mandatory when it was intended to be an offering of support.

- Where people **do** receive SC in their plan, the hours allocated are quite consistently not 'useful' to the person in any practical way that would make a difference in the implementation of their plan or to assist them to navigate the services they need and the system itself.

For example, an aboriginal young man who has complex supports, as well as complex social, financial and material restraints around him and his family, received 12 hours of SC for a year in his plan. These hours would simply be spent getting to know the complexity of the young man and his family, their vulnerabilities and their support needs. Hours needed to connect them with services or therapists to implement their plan would not be possible with 12 hours a year for this vulnerable family.

- When SC is funded, and circumstances change (for example, the SC leaves or a situation requires more time than originally anticipated) there is no easy way to request additional SC hours, other than prompting a review or change of circumstances. Taking funding out of core supports may not always be possible or suitable. It is also time consuming (and therefore uses up funding quickly) when SC's change during the course of the plan. This process uses up funded hours quickly, and also requires a lot of energy for the person to retell their story and re-establish the relationship. This is also compounded when the LAC Partner may also change or leave throughout the plan period so there is no consistent point of contact once the plan is in place.



### **Should the current three level structure of support coordination be retained or changed?**

- WaiS believes reconsidering the three levels would be of benefit to people as sometimes these three levels are confusing for people and their families in understanding the different roles of each level, who to go to, skills required for each role etc.
  - There could be more flexibility of roles, in relation to the allocation and implementation of Support Connection, Support Co-ordination and Specialist Support Co-ordination

For example, people have at times, even when they do not want or need them, been allocated a mandatory SC and a mandatory SSC, in the name of 'safeguarding'. This means people and their families have needed to introduce two new people into their life for a system requirement. Consistent feedback from people and families is that IF they HAVE to have someone providing support, then ONE person would be much better, but with increased flexibility of the role.

- If support connection is to continue, it could be offered as a separate and dedicated funded role at the point of plan approval, so they could immediately be connected to someone that can help them navigate what they might need and how to implement their plan. This could be LAC partner role or a separately funded role.

WaiS have examples of LACs spending extremely limited amounts of time with people and their families, and not having the time to talk to them about their plan or how to understand it, and at times, when LAC's have been turned to for support, people have been told "go google it".

### **What can or should be done to address the level of utilisation of support coordination in plans?**

- Effective allocation of SC hours in the plan
  - For people to utilise their SC, they need hours of SC that is helpful to them, that reflects their needs and can facilitate plan implementation. If people get a small number of hours of SC, it becomes more of a burden than an assistance to engage one so they avoid it.
- Information and support
  - Tailored and effective information and support from LACs and Planners once a plan is approved to explain what is in the plan and how it can be used, would assist people to understand the benefit of support coordination and consequently increase



their desire to use their funding for a support coordinator. For many people, they do not understand what this is for and how to connect with a support coordinator.

For example, WaiS met with a family who were two thirds into their plan period when they connected with us. It was only once we explained what a Plan Manager is and their role, as well as what a Support Coordinator is and their role, did they feel confident to go looking for both a Plan Manager and a Support Coordinator, both of whom would then assist in accessing and paying for supports and services.

- Increase diversity through intentional market development.
  - Intentional work needs to be done with Aboriginal organisations and people/organisations with CALD background/experience who are interested in offering support coordination. This is an extremely thin offering on the ground across both the metropolitan and regional areas.

### Understanding the role of a support coordinator

#### What functions should a support coordinator perform? Are there tasks that a support coordinator should not do?

- One function that needs to continue is linking people with supports and services (funded and unfunded) they may want and/or need.
- Intention and clarity of the role of SC (and the power they have) to be clearly articulated for all (including SC / SSC).
  - Strong messages from the NDIA re the role of a support coordinator is to stand with someone and facilitate/support them to use their plan and get the supports and services that they need and **NOT** to stand against someone nor exert power over someone. However, WaiS has many examples of the contrary.

For example, WaiS has supported many people, with Support Co-ordination who, with the limited history the SSC/SC may have of the person and their family, identify that guardianship is required for the person and consequently commencing the application process for one. With one experience, the support coordinator wanted to pursue guardianship despite a network of informal people who knew the person well expressing that a guardian is not needed. And, in fact, expressing that the person once had a guardian with no positive effect and ultimately resulted in the



guardianship order being removed because it was ultimately concluded she did not require nor benefit from one. All of this information was disregarded by the SSC and she continued her application – which was rightly refused by the Tribunal.

Another common example is where a person may already have a legally appointed guardian, and the SC does not feel comfortable to stand 'with' the person where there may be conflict, and not comfortable to get advocacy involved, even though the person's voice was not being heard in any way. The 'default' at times has been to stand with the people who have the most power, and that is often not the person who needs support.

Many people and families we are connected to have had / known people whose experiences of SC and SSC have been extremely negative and anxiety producing due to SC/SSC recommending and making guardianship applications for an independent guardian to be appointed which impacts on people wanting to engage one at all.

- What could be contributing to this overstepping of role and power imbalance is that it is actually not clear what the ethical parameters of a support coordinator's role are. There are extremely broad outlines of key responsibilities with no associated detail, underpinning values nor boundaries provided. This is reflected in the lack of oversight training available to support coordinators – which has become obvious is needed given the pivotal role a support coordinator can play in a person's life in supporting them.
- Support coordinators should operate from a place of recognising that people are presumed to have decision-making capacity and have the right to self determination and embed supported decision making in their practice.

**How could plan management and support coordination be more closely aligned and what would the potential benefits and risks be?**

- Plan Management and Support Coordination are two distinct roles and serve different functions and should remain as such. The two functions will require different skillsets. Furthermore, there is an inherent conflict of interest if the two functions are conflated into the one role.



## Quality of service and value for money

### Should there be minimum qualification requirements or industry accreditation in place for support coordinators?

- Support Coordinators should not need to have formal qualifications. Qualifications in themselves do not necessarily equate to better quality of service. What is more important is experience and expertise. Demonstrating this experience and expertise during registration process is key.
  - If formal qualifications are mandatory for these roles, it could possibly disregard a number of people that could competently and effectively fulfil the role. This could particularly limit people with disability, culturally diverse groups and family members even though they may have the lived experience, and skills/competencies required for the role.
  - Being able to demonstrate the appropriate experience and expertise will rely, however, on clarity of role and responsibilities which, as highlighted earlier, is currently unclear.
  - A clear and strong commitment for support coordinators to operate with a values base of human rights and supporting people to exercise their legal and human rights, inclusive of the right to choose and self-determine is more critical to the role than qualifications. We recognise that this values based approach is inherent in the NDIS Code of Conduct and Practice Standards but would advocate for the NDIS to consider developing a capability framework specific to support coordination. This framework could focus on the values, ethics, knowledge and skills that underpin effective support coordination.
  - Quality support coordinators need to be able to have knowledge of all options that could be available to people and/or know where to access information if needed. WaiS have numerous examples of NDIA planners, LACs and support coordinators not knowing that there are individualised living arrangements available to people in addition to group homes. As such, only group homes are offered as an option to people as a living arrangement away from home, unwittingly limiting peoples' choice. WaiS also has examples of people not being offered support with a discovery process to assist people to work out more meaningful and valued work in customised/open employment.



## Capacity building for decision making

**How can a support coordinator assist a participant to make informed decisions and choices about their disability supports? What are the challenges?**

**How does a support coordinator build a participant's independence rather than reliance?**

- Information and Support
  - SC need to have an in depth understanding of, and commitment to Human rights and the principles of self direction and supported decision making.
  - Building peoples' capacity for decision making, self direction and independence is a significant responsibility to be included in the suite of responsibilities of a support coordinator. However, to be able to provide this support adequately and effectively requires a support coordinator to be (a) adequately skilled to be able to provide this support; and (b) provided with sufficient allocation of time with which to do this.
  - Support Coordinators should be skilled in supported decision making, underpinned by the right of self determination and the presumption that people can make decisions with the right support. If a support coordinator does not have the required experience and expertise, they should connect to someone else who does, and need to know with whom they could connect with.
  - All information should be provided accessibly, whether this is Easy Read, plain language, Auslan or other languages.

**How can a support coordinator assist a participant in need of advocacy without acting outside the parameters of their role?**

- Clarity is required that advocacy is not a function of a support coordinator, but is a service that support coordinators need to be aware exists for people to be referred to and when this may be needed. In particular, support coordinators need to understand what advocacy is, when it is important to consider linking someone to advocacy services, and who is offering these services.

## Conflict of interest

**In what circumstances is it more or less appropriate for a participant to receive multiple supports from a single provider?**

**Should the NDIA enforce an "independence requirement between intermediary and other funded supports at the participant level"?**





## **What impacts would stricter conflict of interest requirements have on NDIS participants and the NDIS market?**

- WaiS is mindful of restricting peoples' choice by arbitrarily reducing their options due to the prospect of conflict of interest. People should have the right to decide who provides supports including support coordination. If people make an informed choice, that makes sense to them, and their circumstances, to have a single provider then this is their right to choose.
- What then becomes important is providing people with sufficient information to be able to make an informed decision as to the best option for themselves.
- What may also be required is a discernment of particular vulnerabilities and risks which suggest it might be a safer option for a person to choose to have an independent support coordinator.
- Support coordinators also need to have an understanding of what constitutes a conflict of interest and, if a choice is made for a single provider to deliver all supports, the provider needs to ensure the person is able to (and feels they are able to) complain without recourse, if need be, and how to do so.
- WaiS recognises that quality providers often offer support coordination even when they are not funded for it, because they know this is of value and benefit to the person/people they are supporting.