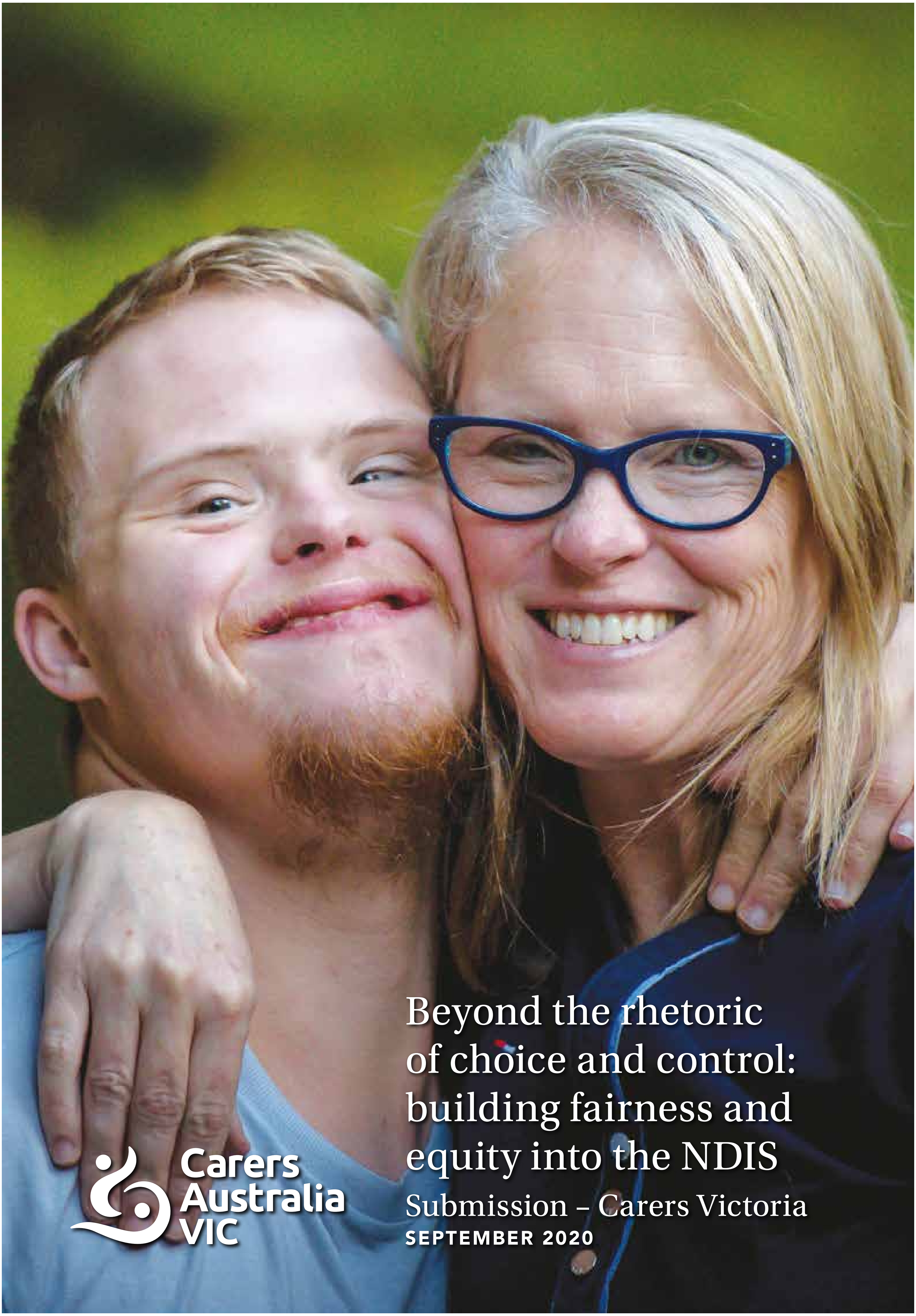

Beyond the rhetoric of choice and control: building fairness and equity into the NDIS

Submission – Carers Victoria

SEPTEMBER 2020

Carers Australia VIC

Contents

Introduction

Carers Victoria welcomes the opportunity to contribute to the NDIA's Discussion Paper about support coordination services.

Our organisation has been a vocal supporter of the NDIS and participated in many consultations intended to improve the design of the Scheme and its implementation. We believe when a system likes the NDIS appropriately recognises the complexities of disability within a familial setting (all forms of family and families of choice are implied), then the long-term objectives of the NDIS will be achieved: capacity building support from an early age, increased opportunities for independent living, economic participation and social connectedness. These outcomes will ensure people with disability have the same opportunities to make friends, find jobs, remain safe and enjoy the amenities Australia has to offer like everyone else.

However, Carers Victoria is concerned the NDIS was designed to rely too heavily on informal supports to fill in gaps in paid supports and does so at the expense of the wellbeing, job opportunities and financial security of carers, particularly women.

The term carer is inclusive of partners, family members and friends who are involved in the care of people with disability. It does not refer to people who provide support as a paid worker, employee or volunteer.

Addressing the problems in the area of support coordination, the NDIA will be able to resolve the lack of fairness and equity in the Scheme for carers and increasing pressure on care relationships; however, further work is required for a fully functioning Scheme which does not negatively impact on the natural supports of people with disability.

An Informed Response

This response is informed by significant engagement across Victoria via face-to-face and online service delivery and consultation with carers of NDIS participants prior to, and during transition to, full scheme in the State as well as organisations' delivery support coordination, advocacy and non-NDIS-funded services. We have used case notes of one Carers Victoria client and testimonials of carers who have shared their true stories. These use pseudonyms to protect confidentiality and de-identify contributors.

In 2016 Carers Victoria was one of the original 20 disability support organisations which partnered with the NDIA to deliver face-to-face NDIS education workshops on pre-planning and post-plan implementation; peer support programs including online support; direct support through NDIS Advisors to assist with access, pre-planning and plan implementation challenges; and information provision to families who use DHHS-run out of home respite facilities regarding the divestment of service provision in 2018-19.

In 2017 Carers Victoria consulted with over 1500 carers in face-to-face and online forums to inform the development of the whole-of-government Victorian Carer Strategy 2018-22.

These interactions consistently highlighted the challenges carers face when interacting with NDIA staff or their Local Area Coordinator. Without these insights, the data published in the Discussion Paper is compromised. While our evidence is anecdotal, we challenge the NDIA to collect and publish rigorous, longitudinal data which demonstrates the extent to which support coordination can influence and shape the lives of carers, their ability to maintain or increase participation in the paid workforce or further study and their wellbeing.

CARERS VICTORIA RECOMMENDS the NDIA significantly reform its provision of support coordination by recognising it as a reasonable and necessary support for carers. Doing so, will build fairness and equity into the Scheme for carers.

What was your role in obtaining a National Disability Insurance Scheme plan?

> *"Meeting with the planner, approving the plan and now self-managing, establishing service agreements with providers and trying to set up extra-curricular activities, also sourcing carers now that we have funding to have them."*

Carer survey respondent

Carers need a fair and equitable NDIS

It is well recognised the NDIS is a significant mechanism in Australia's overall strategy to increase equity and inclusion of people with disability with the provision of individualised specialist disability services that are chosen and managed (to varying degrees) by the services users.

Some of the challenges that have beset the Scheme during the rollout phase can be appropriately termed 'market failure' - where services are not willing to service consumers or 'cherry pick' clients whose identity and disability(s) facilitate less complex transactions and increase profit margins. People with disabilities who have behaviours of concern, who are from culturally and linguistically diverse backgrounds, live in rural and regional areas require services with more complexity.

An increased demand on families and carers who are required to provide additional care without support or assistance themselves is a significant and detrimental consequence of market failure.

However, this increased demand on carers, a lack of awareness about the supports which can sustain care relationships and a wide refusal to fund them is built into the current NDIS. Carers do not experience fairness and equity that the NDIS is intended to achieve because their needs are constantly seen as secondary in comparison to the person(s) for whom they care and a threat to the viability of the Scheme.

The problems that characterise the approval and utilisation of support coordination in plans are emblematic of plan utilisation more broadly and specifically the assumption that the NDIS is not meant to replace parental roles and responsibilities. This normative assumption underpins the NDIA's approach to defining reasonable and necessary supports for each participant. Such an assumption is problematic because planners are under no obligation to carefully consider, understand or assess every individual family's unique capacity to provide supports to participants.

This assumption is based on an erroneous idea that comparison with other Australian families is a baseline with which to measure what can be considered reasonable and necessary but actually, this approach further entrenches hidden and unpaid labor which underpins the paid disability workforce. **Without the hidden unpaid labour of carers, the current disability workforce is likely to be overwhelmed and more dysfunctional.** The total estimated hours of care nationally is 2.2 billion in 2020 – this equates to a total national replacement of all informal care of $77,910.7 billion. This reflects an increase of 29 per cent since similar research was last conducted in 2015.[1] The total estimated hours of care in Victoria is $19.4 billion.

As the Discussion Paper notes, support coordination is a conduit to other services in an individual's plan. It's role in the utilisation of other funded supports needs to be carefully examined by independent research. Ultimately, effective provision of support coordination should reflect a realistic understanding of each family's unique capabilities, aspirations and objectives.

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[1] *The value of informal care in 2020 Deloitte Access Economics Report for Carers Australia May 2020*

Every family is unique

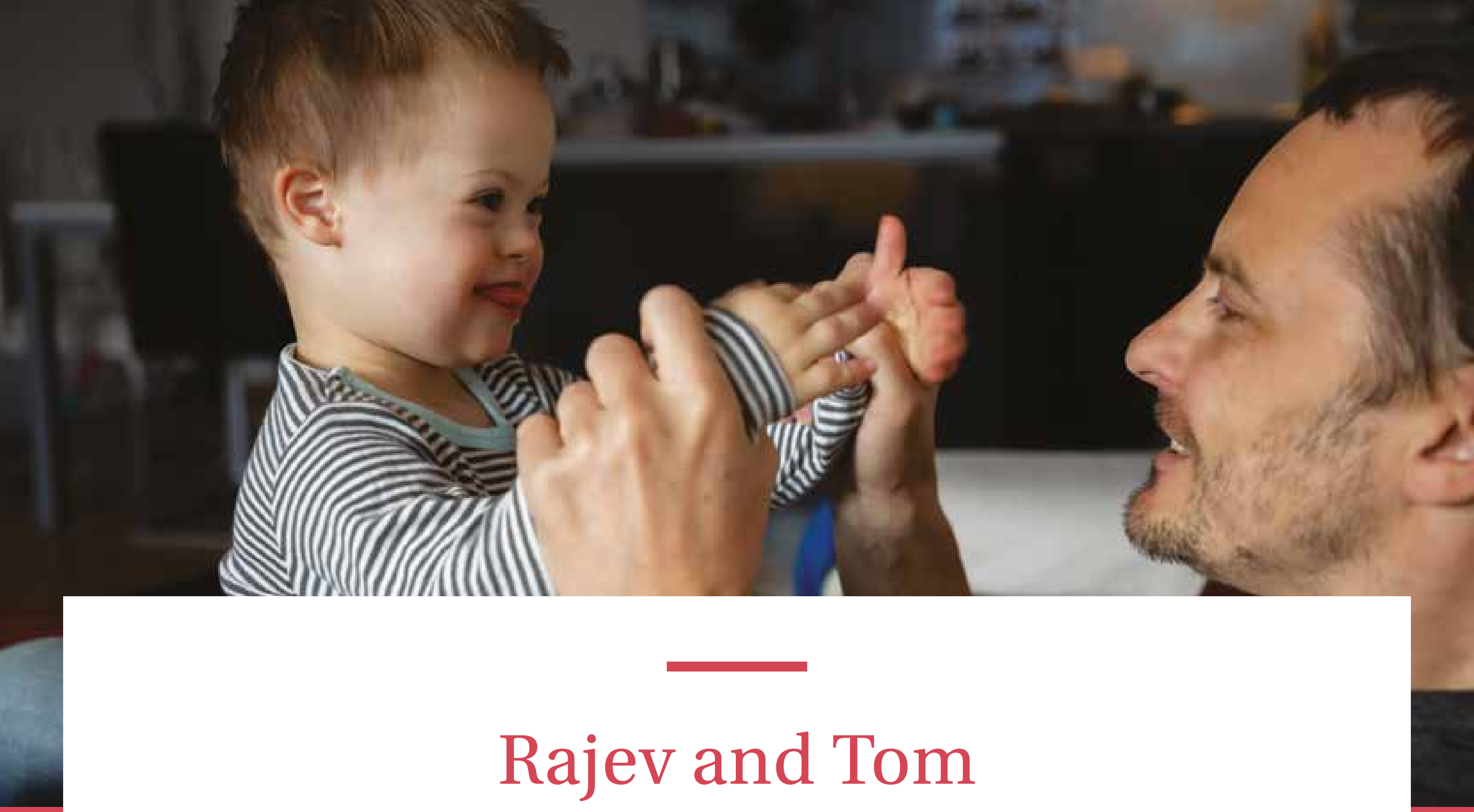
The assumption that the NDIS is not meant to replace parental roles and responsibilities is particularly evident in the plans of participants aged 14 years and under. It is not surprising these cohorts of participants have the lowest levels of support coordination funded in their plans (Table 2). This is directly related to the premise the Agency has that carers undertake this role as if there is an equivalent role in parents of typically developing children.

Yet assumptions are made about what other parents do when raising children without adequate recognition that raising children with disability adds a specific layer of complexity to family situations and dynamics.

What was your role in obtaining a National Disability Insurance Scheme plan?

> *"I had to sort everything out and complete the paperwork. I've had to do chasing up and initially liaising with support agencies. I have to deal with phone calls, emails and make sure my adult daughter attends appointments. I also have to make sure when possible she participates in the activities provided for her."*

Carer survey respondent



Rajev and Tom

Rajev is the carer for his one-year-old son Tom who suffers from multiple and life-threatening disabilities. Tom requires supervision while awake and active monitoring during the night. Rajev works full-time but due to his wife's limited English skills and inability to drive, he manages all medical and disability related requirements for Tom and drives both his wife and son to all appointments. Rajev needs to take considerable time off work to perform these tasks. Rajev and his wife are struggling to understand the service system and find appropriate services for their son.

At their first NDIS planning meeting Rajev requested support coordination to help them navigate the disability support sector and implement the NDIS plan. Despite having appropriate supporting evidence and the obvious limitations with communication, the LAC denied the request citing that it was not reasonable and necessary as "all parents of children as young as yours are expected to take their children to organise their child's supports" and that support coordination was not available for children under seven unless in exceptional circumstances.

Rajev requested a further planning meeting and received help from a Carers Victoria adviser to demonstrate their need. This process took considerable time and effort on Rajev's part resulting in more time off work and increased stress as Rajev worried about the security of his job.

Whilst this request resulted in a delay in receiving a plan, it also resulted in allocation of support coordination. Unfortunately, Rajev struggled to identify and secure a support coordinator on his own, further compounding the issue. However, once the support coordinator commenced, they assisted Rajev and his wife to understand the NDIS and start services in a way that would not be achieved as comprehensively or quickly if they were to try and achieve this on their own.

In the four months since they have been receiving support coordination, Rajev has had to spend less time navigating and managing his son's supports, he feels less anxiety about his job security and the quality of his son's care. Rajev advises that he would not have been able to implement his son's plan without the support coordinator.

Current critical issues in support coordination for carers

WHAT WOULD YOU IDENTIFY NOW AS THE CURRENT CRITICAL ISSUES AROUND SUPPORT COORDINATION?

- Low numbers of support coordination approved in plans especially for participants aged 0 to 14 years. Thus the NDIA has created artificial market of low demand. Competition and innovation does not follow from low market demand.
- Participants whose plans include support coordination are not intended to be supported by LACs beyond the approval of the plan. Yet, LACs do not always inform carers that support coordination is included in the NDIS plan. The assistance of a support coordinator is unused simply because the participant and carer remain uninformed.
- Without adequate assistance, support coordination can be as difficult to find and engage with as other disability or mainstream services.
- Support coordinators have significant caseloads which are highly likely to impact on quality service delivery.
- The quality of support coordination is variable and like all other disability services is dependent on location and luck.
- Thin markets in support coordination can have a self-censoring effect on carers raising their concerns about the quality of support coordination.
- Atomised service provision including a lack of connectedness between planning delegates (NDIA or LAC-based), support coordinators and other disability services hinder plan utilisation and increase pressure on carers to fill in gaps.
- The preferred NDIS business model of self-contractors can be detrimental to consistent service delivery which will undermine the long term objectives of the NDIS - these service may have high turnover from burn out and short term contracts.
- Planning delegates do not adequately evaluate support coordinators for quality services delivery.

The NDIS will be a fair and equitable Scheme for carers when…

ONE

Determinations of support coordination in a plan are made once an assessment of the carer's capacity to support the participant in a range of domains is made in good faith.

TWO

The Agency issues guidance that support coordination is to be discussed and offered in any situations where literacy, cultural, socio-economic and/or the health of the carers may be a barrier to the timely and successful implementation of supports.

THREE

Planning delegates ensure participants and carers have made a service agreement with a support coordinator, recording this in the NDIA's internal data management system. Planning delegates follow up with carers two months after plan approval.

FOUR

The Agency develops a set of key performance indicators that planning delegates must achieve to support all parties to the care relationship to identify their own preferences in support coordination.

FIVE

Planning delegates discuss the potential for successful implementation and plan management to compromise the capacity of carers to continue in or enter the paid workforce.

SIX

Planning delegates conduct adequate inductions with all parties to the care relationship once the plan is approved.

SEVEN

Interactions between support coordinators and other NDIS supports is made as seamless as possible, reducing the unpaid labour carers contribute to supporting NDIS plans.

EIGHT

Support coordination is funded to allow for identifying and securing non-NDIS funded supports within mainstream services, reducing the unpaid labour carers contribute to supporting NDIS plans.

NINE

The NDIA and NDIS Quality and Safeguards Commission collaborate to develop adequate evaluations of support coordination from both an individual client perspective as well as a broader workforce perspective.

TEN

The Independent Advisory Council's (IAC) recommendation regarding independence between intermediary and other funded supports at the participant level is enforced by the NDIA and NDIS Quality and Safeguards Commission.

Fiona and Nancy

I am the plan nominee for my 18-year-old daughter who has an intellectual disability, autism and ADHD. We live outside of Melbourne. She has what the NDIS describe as 'behaviours of concern'. We are into our 3rd year of the NDIS but have had several plans due to errors in some and underfunding. Delays in getting a review, approval and a new plan left us without supports that then led to a deterioration in my child's capacity, an increase in her challenging behaviours, withdrawal of existing service providers and a deterioration of our ability to care for her which meant we needed another plan review.

In the first 18 months of the NDIS we had seven support coordinators. Only one of these changes was at our request and one was because we had to change from a normal support coordinator to a specialist one. The others were because the person left the service to start their own NDIS business, found a more permanent job or found the job too stressful. This was very stressful and added a lot of time for me in trying to manage my daughter's services between coordinators or having to bring new coordinators up to speed. I know it was also frustrating for my child's school staff and other service providers who had to keep making time to brief each new coordinator. It also meant getting new services started were held back while each new coordinator "found their feet". We also had to use up a lot of our support coordinator hours because of the handover notes and meetings each coordinator had to do when they left. Luckily, we had our last coordinator for 18 months before he retired.

Even though it was good to get specialist support coordination in my daughter's plan, I wasn't able to use them in the way I hoped. For example, we needed and still need help with planning my daughter's housing, challenging behaviours and her transition from high school to adult life. We haven't had any support coordinator who has skills and experience in all these areas. It means I am still needing to spend quite a bit of time researching and working on my daughter's' disability supports. I imagine larger organisations might have specialists in each area that can help each other out but in the country or smaller services this would be hard.

Also, our support coordinators haven't been able to solve our problem of finding and keeping specialist services in our area. So, I am still spending a lot of time doing this in addition to managing her needs that are not covered by the NDIS.

Responses to discussion paper questions

This submission responds selectively to questions and maintains question numbering consistent with the Discussion Paper.

QUESTION 1. What factors should be considered when determining if, when and for how long support coordination should be funded in an NDIS participant's plan?

All families are unique. Any determination of support coordination in a plan should be made once an assessment of the carer's capacity to support the participant in a range of domains is made in good faith. An assessment in good faith does not proceed from the basis carers should fill in gaps created by a distorted disability market resulting from poor market stewardship. Carers should be able to express what interest and/or capacity they have to undertake this role, including current and future skills which may be suitable to utilise.

The Agency should issue guidance that support coordination is to be discussed and offered in any situations where literacy, cultural, socio-economic and/or the health of the carers may be a barrier to the timely and successful implementation of supports.

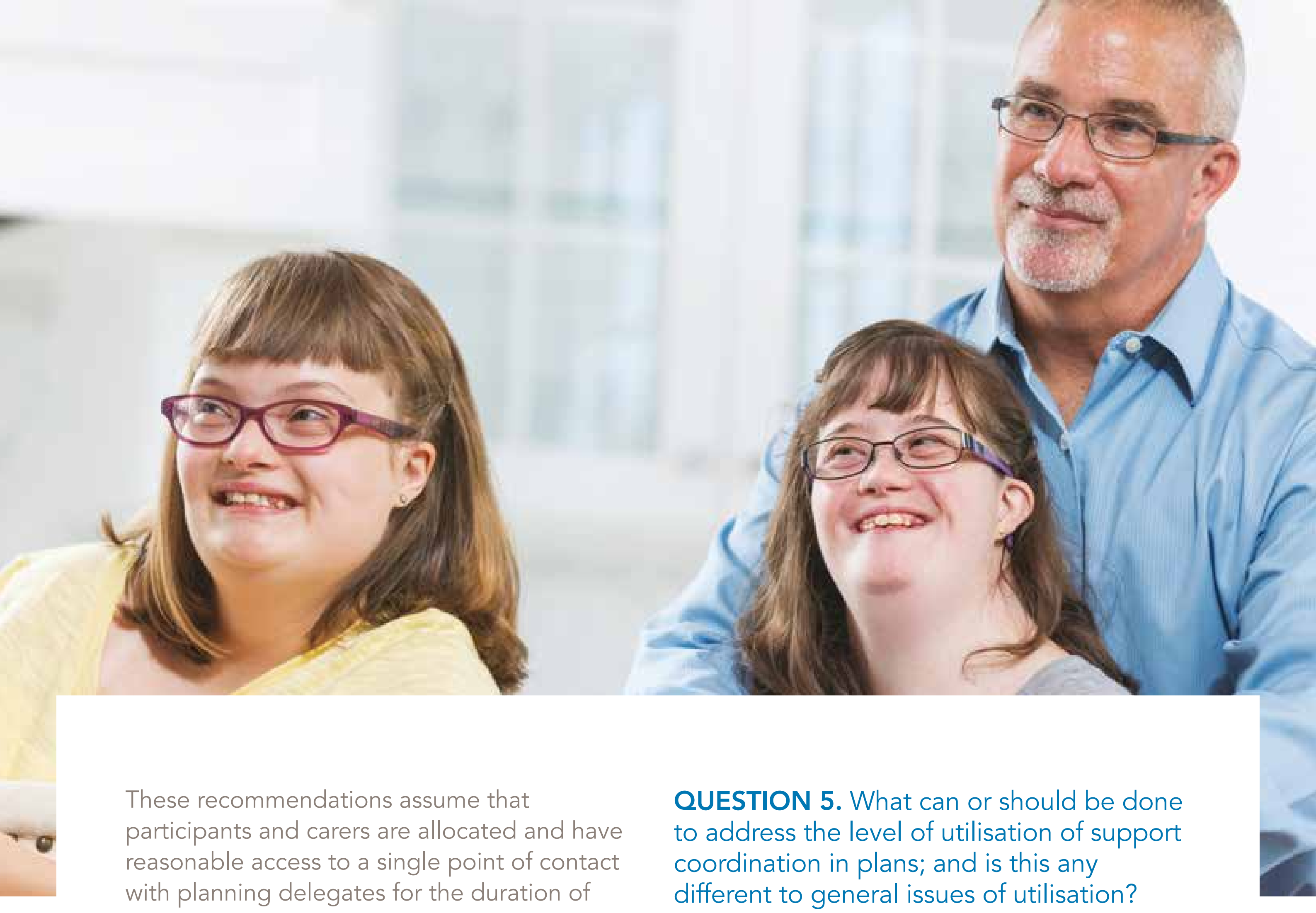
Further, support coordination should be discussed and offered when the successful implementation and management of a plan will compromise the capacity of the participant and/or carers to continue in or, enter the paid workforce.

Finally, the Agency should adequately fund support coordination to successfully implement the participant's plan and allow for liaison with service providers to coordinate annual reports.

QUESTION 3. How should support coordination interact with other NDIS supports? For example, local area coordinators, community connectors, liaison officers and recovery coaches?

To fully realise the ambitions of the NDIS, the NDIA should ensure interaction between support coordinators and other NDIS supports is as seamless as possible. To facilitate this, planning delegates who are the first meaningful point of contact for participants and carers, should assist participants and carers to secure and evaluate support coordinators. This requires time between planning delegates and participants and carers to broadly discuss the role of support coordination and the approved level obtained in the person's plan. Planning delegates should assist participants and carers to identify potential support coordinators and discuss the issues that may impact on engagement, such as waitlists and complexity of supports.

The next step is for planning delegates to ensure support coordination has commenced and the internal data management system to record confirmation and flag if not. This would address the common issue of delays or failure to commence supports when participants do not realise they have been allocated a support coordinator, do not have the capacity to find and secure one or do not understand what a support coordinator does.



These recommendations assume that participants and carers are allocated and have reasonable access to a single point of contact with planning delegates for the duration of their plan as per the proposed NDIS participant service guarantee. This same contact should be made available to the support coordinator. Any change in the planning delegate must be communicated to the participant and carer as well as the support coordinator and a handover or introduction be made.

QUESTION 4. How should support coordination interact with and complement existing mainstream services?

Support coordination should be funded to assist in identifying and securing non-NDIS funded supports within mainstream services. This recognises the barriers many participants and carers face in accessing mainstream services and community activities without appropriate support. The NDIA should collect data which measures access to mainstream services and community activities as a reflection on its investment.

QUESTION 5. What can or should be done to address the level of utilisation of support coordination in plans; and is this any different to general issues of utilisation?

The NDIA should develop a set of key performance indicators that LAC and NDIA planning delegates must achieve with the intention to support participants and carers to evaluate and secure support coordinators. Area managers should monitor plan utilisation and record and follow-up over or under-utilisation with local planning delegates, participants, carers and/or support coordinators.

QUESTION 6. What functions should a support coordinator perform? Are there tasks that a support coordinator should not do?

Support coordinators should be able to perform the following functions:

- Coordinate development and implementation of service agreements with service providers in close consultation with participants and carers
- Review efficacy of engaged support providers and discuss with all parties to the care relationship any challenges encountered
- Coordinate care team meetings

- Establish and manage the shared communication system between both NDIS funded and other supports
- Ensure other service providers provide appropriate reports in time for unscheduled and scheduled plan reviews
- Provide a report about their own efficacy
- Ensure participants and carers are adequately prepared for plan review
- Liaise with planning delegate where requested by client

QUESTION 7. Is there evidence that participants with specific plan goals related to education, accommodation and employment would benefit from more targeted support coordination services to achieve these outcomes?

Current evidence is mainly anecdotal. There is broad consensus many participants and carers utilise their own resources to source these services themselves if their support coordinator does not have expertise in this area or does not undertake the research or networking to achieve the outcomes. Like other attempts to secure specialist disability supports, these are unlikely to be efficient, causing anxiety and perhaps distress. There is likely to be an additional cost burden to the Scheme or the wider community if goals are not achieved with sufficient assistance from experts in disability services.

The capacity to secure and maintain these supports is likely to be greatly enhanced with the assistance of support coordinators specialising in obtaining specific goals in NDIS plans.

QUESTION 9. Should there be minimum qualification requirements or industry accreditation in place for support coordinators? If so, what might be applicable?

Carers Victoria has frequently raised issues of workforce quality about the disability and aged care workforce in both State and Commonwealth forums. Our organisation believes there is an artificial division between the two and ultimately sees the creation of a regulatory body which oversees the social care workforce similar to that which has operated in Northern Ireland for over 15 years as a model to adopt and adapt in Australia.

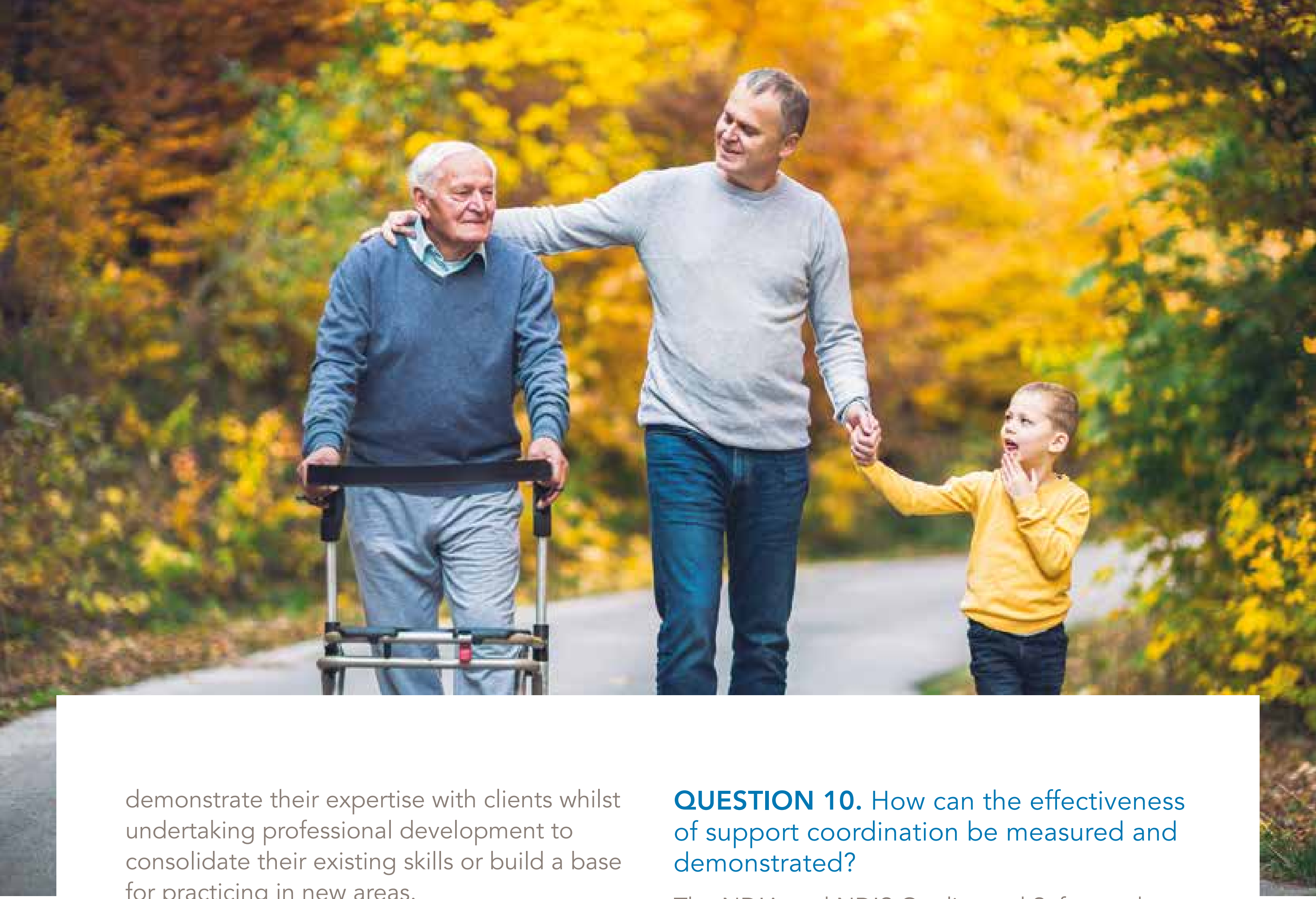
Countless investigations including Royal Commissions have demonstrated one factor currently inhibiting the improvement of the workforce is the apprehension to impose a basic functioning regulatory system with worker registration, continuous professional development and public registers of excluded workers at its core.

Fears such regulation is burdensome for business do not outweigh the need to prioritise the safety of people with disability and their families. These fears are ultimately counterproductive – poor oversight leads to poor service delivery and outcomes, distrust in consumers and withdrawal from paid supports, not to mention a poor return on the community’s investment in the NDIS.

Carers Victoria believes there are mechanisms which can be used to improve the standards of support coordination delivered through the NDIS to the benefit of consumers and the workforce.

The means of entering the workforce as a support coordinator is likely to be varied. At the heart of the role is leadership, expertise of social models of disability and legal frameworks supporting inclusion of people with disability, knowledge of disability services, problem solving and conflict resolution. Good support coordinators are likely to have undertaken higher education and obtained professional experience demonstrating their leadership and problem-solving expertise.

A registration scheme for support coordinators would enable people with qualifications and experience in different sectors to apply for basic registration and subsequently



demonstrate their expertise with clients whilst undertaking professional development to consolidate their existing skills or build a base for practicing in new areas.

As both the NDIS and registration scheme matures, support coordinators should be expected to demonstrate their competence in effectively achieving outcomes for clients in areas including but not limited to:

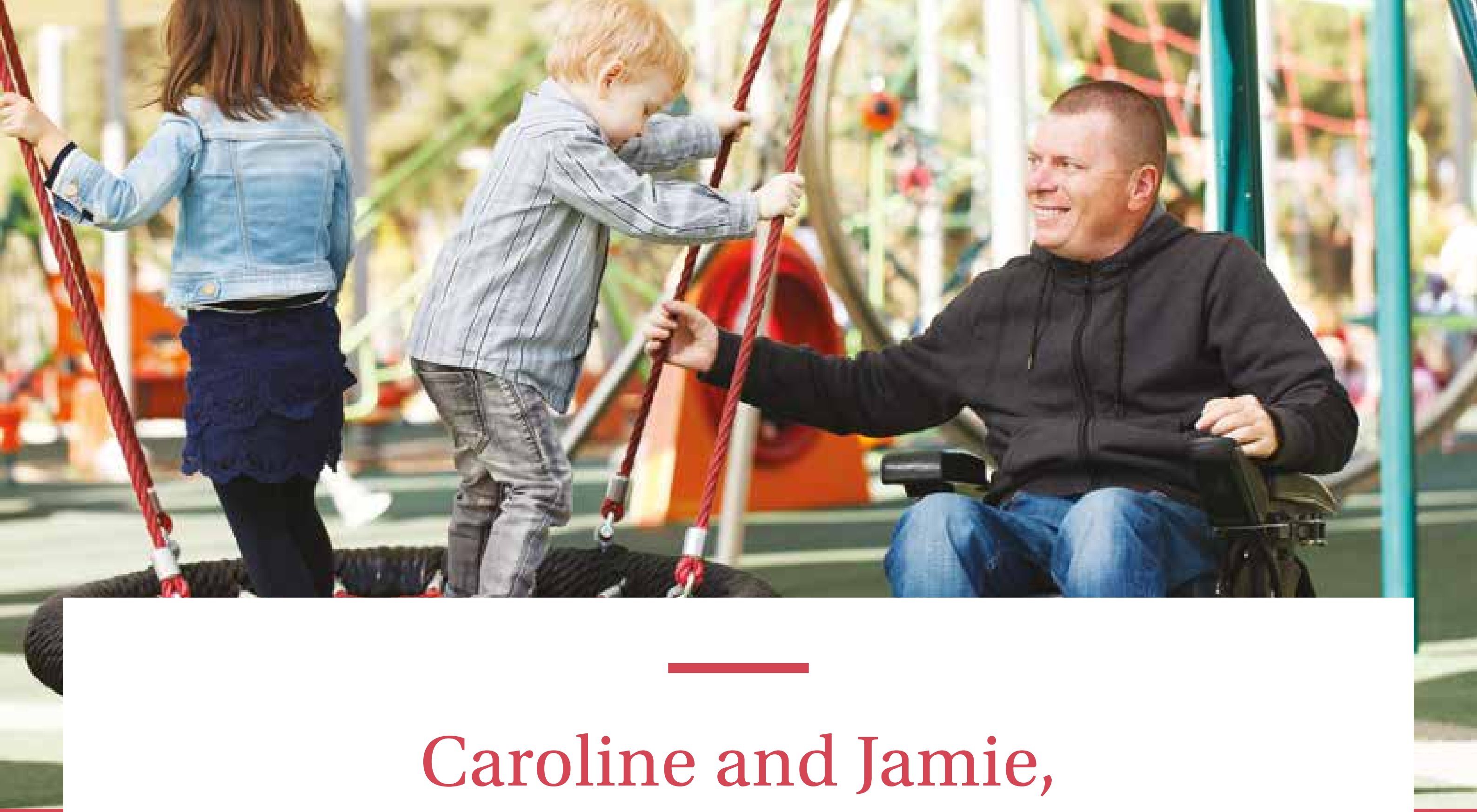
- specialist disability accommodation
- mainstream housing
- positive behaviour support
- employment for school leavers and other employment supports
- education, and
- working with people from marginal communities including Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds and people who identify as lesbian, gay, bisexual, transgender or intersex.

QUESTION 10. How can the effectiveness of support coordination be measured and demonstrated?

The NDIA and NDIS Quality and Safeguards Commission should collaborate to develop adequate evaluations of support coordination from both an individual client perspective as well as a broader workforce perspective.

Participants and carers should be closely involved in developing measures to assess the effectiveness of their own support coordinators and contribute to the knowledge of the NDIS consumer community. The inclusion of subjective measures about levels of trust and power between clients and support coordinators are important. Participants and carers can be assisted by planning delegates to evaluate the support coordinators' means of communication with clients, clarity of expectations for all parties; achievements and outcomes such as contracting service provider(s), negotiating terms and expectations as well as accounting for use of time.

However, objective measures regarding competence must also be used such as plan utilisation, outcomes generated from services, level of turnover in services and agreed methods for conflict resolution.



Caroline and Jamie, Ben, Suzie and Freya

I am the parent of four children, three of whom are NDIS participants while another is awaiting a decision about eligibility. Recently, I became eligible for an NDIS plan myself.

Support coordinators have had a crucial impact on our children's capacity to live ordinary lives. They play an important part in successful outcomes. I know this because I've experienced both 'very good' and 'very poor' support coordination. My second child who has the more 'severe' disability and our family are still living with the trauma that poor support coordination has created – over five years later.

My eldest child was enrolled in the NDIS trial site in Barwon at the age of two and that support coordinator was an employee of a well-established disability service provider.

It was often difficult to get a response from the support coordinator and I often felt I was putting her out simply by contacting her with questions relating to the plan. Usually, nothing progressed without me following up. Responses were often terse and condescending leaving me confused about what her responsibilities were.

The NDIS portal was in its early stages but the support coordinator was able to monitor my child's plan. I was concerned about the accuracy of funding levels, but when I queried this she encouraged us to book respite because we should 'use it or lose it'.

Soon after the respite provider with whom we had regular bookings, called to advise us there was no funding left and pulled all supports without any notice. With no money left all supports were cancelled and, with a newborn baby - our fourth child, this sudden change had drastic consequences.

The impact of this loss of routine for my child was immense and devastating to our family – it meant the progress made in toileting and being able to wear underwear at least some of the time was completely undone and he ended up in hospital. My husband was at his side which prevented his ability to work at all.

In the year that followed my daughter began showing signs of anxiety and began seeing a counsellor, my husband left Australia to undertake a fellowship he'd committed to the previous year when things were ok - a rare opportunity to enhance his career prospects - but he left me to care for four children – two with very high needs.

I happened to contact a social worker out of desperation. She suggested I should change providers because what we'd experienced was beyond excusable. It was the first time in a long time I took my own concerns seriously. My husband had pointed out the support coordinators dismissive attitude to me prior to the funding debacle but I'd given her benefit of the doubt.

Huge delays were caused by the support coordinator and the new provider did not obtain authority for our son's plan for two months This only occurred because I complained to the CEO and GM, threatening further action with the Ombudsman. When I queried the cause of the delay, the support coordinator admitted she had been prioritising her upcoming interstate move to a new job. Rather than handover her caseload to a colleague, she set everything else aside to organise her move. I did vehemently complain to the employer but I had too much on my plate to follow this up further when they did not respond.

In contrast, our current support coordinator is fantastic. She has just resigned from the organisation she was employed at to be an independent contractor. We followed her because of the trusting relationship we have developed over many years. One thing that is psychologically taxing about having many children with disability and my own, is the amount of time having to 'tell our story', explain circumstances and provide background information and justification. That's not necessary with our current support coordinator, as she knows our family and needs extremely well, and is happy to do a large portion of that part for us if needed when engaging new providers; including filling in the forms before our first meetings. Those things make a huge difference.

We are a family of six and four people have NDIS plans - soon to be five - so our needs are very complex. We trust that our support coordinator is on top of our NDIS budgets – in fact she's likely to err on the side of caution and underspend so we're not in the position we found ourselves previously with all that has entailed for my eldest child and family since.

Our current support coordinator is able to guide us through a landscape which is constantly changing and evolving much faster than we could possibly keep up with. It's more efficient for her to do the research as she has a better idea of what to look for rather than us wading into deep water, not to mention the burden of paperwork.

From my experience I would suggest support coordination is a vital service and would be important for the majority of participants. I think it would be very time consuming, confusing and emotionally taxing to find appropriate services and make the most of funded supports.

It does concern me that some people may be taking this job who aren't suited to meet their clients' needs. The government's money will be utilised in the best possible way when participants experience improved quality of life and ability to contribute to the community through the assistance of an experienced and proactive support coordinator.

QUESTION 11. Are there emerging examples of good practice and innovation in support coordination?

Larger providers have demonstrated good practice by sharing resources among support coordinators in relation to speciality portfolios. The establishment and management of care teams and family circles of support are also examples of good practice and innovation in support coordination.

QUESTION 14. How can a support coordinator assist a participant to make informed decisions and choices about their disability supports? What are the challenges?

Carers Victoria strongly believes adequate time is needed to develop rapport, trust and understanding.

Every NDIS participant and carer is unique and their capacity to make informed decisions will depend on how support coordinators make accommodations to communicate effectively about available options. This reflects the social model of disability and puts the onus on support coordinators to develop and use appropriate resources such as factsheets in Easy English, the person's first language or other communication devices the participant or carer utilises. The NDIA can facilitate this by holding a public repository of factsheets and referrals to communication assistance specialists which are updated as necessary.

To assist participants and carers to make informed decisions support coordinators need to know the preferences, needs, concerns and ideas about the services needed. Challenging low expectations may also be necessary. With such basic information, support coordinators can begin the process of research and selection of services and present their recommendations to their clients for final approval. Further, support coordinators can encourage participants and carers to ask questions, raise concerns with the support coordinator and other services and understand their own responsibilities of engaging with service providers such as knowing cancellation policies, payment processes and service agreements.

Another means of facilitating decision-making are templates which capture common features for each service over the cycle of a plan. These may include: "selecting my service", "my service agreement with X provider", and "reviewing my service". It is intended the participant is appropriately supported to take an increasing role in leading each activity.

For these approaches to be successful, support coordinators need to understand what capacity the participant or their carer has to manage this process and be sufficiently funded to ensure the time needed to coach and assist in supported decision making processes does not compromise completion of other support coordination duties.

QUESTION 15. How does a support coordinator build a participant's independence rather than reliance? Should support coordination pricing be determined, at least in part, based on building a participant's capacity for decision making to become more independent?

Carers Victoria has partly addressed this issue in question 14. While independence and reliance are important aspirations of the NDIS and disability inclusion strategies more broadly, these are not the only means to measure the success of the Scheme, especially after a challenging implementation period.

We believe this question does not fully appreciate that aspirations of independence for NDIS participants and carers are likely to be counter-productive without appropriate mechanisms in place. This includes adequately understanding the physical and mental impact of historical and current policies which result in segregation, low expectations, crisis-driven services, violence and exploitation.

The ability for support coordinators to assist their clients build independence in a disability services market does not occur successfully in a context of poor market stewardship, natural disasters or the COVID-19 pandemic. These external forces significantly impact the growth and quality of the disability services market which then create and contribute to thin markets. Thin markets are a key factor in reluctance of participants and carers to exercise their independence and challenge service providers for better quality. They are likely to be labelled 'troublesome' clients and have services withdrawn.

Carers Victoria does not recommend that support coordination pricing be determined in any part on building a participant's capacity for decision making to become more independent until the Scheme has further matured. This view is problematic and likely to create more risks for NDIS participants and carers because it ignores the structural barriers which continue to limit their independence whilst putting the onus on individuals who cannot significantly influence these structural barriers.

QUESTION 16. How can a support coordinator assist a participant in need of advocacy without acting outside the parameters of their role? What are the appropriate parameters of the personal advocacy role and the support coordination role?

The rollout phase of the NDIS has demonstrated beyond doubt that advocacy services are necessary safeguards for participants and carers throughout the entire journey including meetings with planning delegates, reviews and service provision. In Victoria existing disability advocacy services have been overwhelmed by complaints about NDIS processes and have limited capacity to address other issues raised by their clients.

Support coordinators should be able to work with advocacy services and provide their expert advice about the efficacy of disability services and provide evidence to support a participant or carer's claim about the provision of a service. Support coordinators should be able to advocate for clients as long as this advocacy is not intended to be in the best interests of the support coordinator. Support coordinators should be able to detect a conflict of interest in their assistance for clients and should declare that conflict to participants and carers.

Support coordinators' attendance at planning meetings is an area which requires thorough examination to ensure the long-term objectives of the Scheme are reached – not just the short-term goal of underspent budgets. The fact support coordinators can be important in negotiating better outcomes at plan review meetings is a poor reflection on the NDIA's approach to plan development. It is likely to signify planning delegates do not fully appreciate or understand participant and carers' needs and goals rather than overreach by support coordinators.

QUESTION 18. Should the IAC recommendation for the NDIA to enforce an "independence requirement between intermediary and other funded supports at the participant level" be adopted?

Carers Victoria believes the IAC's recommendation should be enforced by the NDIA. The NDIA and NDIS Quality and Safeguards Commission should carefully monitor that this is genuinely implemented to avoid the unintended consequences of service providers setting up separate 'shell' companies without declaring a conflict of interest and/or surreptitiously referring clients to a company to obtain commissions. Similar practices were investigated by the Commonwealth Royal Commission into Misconduct in the Banking, Superannuation and Financial Services Industry which showed the financial, physical and mental wellbeing of consumers was secondary to the greed of companies and individuals. Carers Victoria believes separation of interests is a key indicator of effective market stewardship and will ultimately create a robust disability services market.

Miriam and Theresa

My name is Miriam and I am one of many carers supporting my aunt who has been an NDIS participant since July 2016. While Aunt Theresa lives independently in public housing, she is regularly supported by her adult sons and another niece who provide care in different ways - from attending appointments for medical and health purposes to shopping and diary management.

Theresa's disability significantly impacts her ability to communicate with others and her mobility. These functional limitations were caused by a stroke when Theresa was in her early 40s and a mum to two young boys.

I have helped to manage Theresa's self-managed NDIS funds since 2018. I work at a community services organisation where I learnt about the NDIS and I became increasingly concerned about the self-serving behaviour of Theresa's support coordination service which also employed her support workers to undertake cleaning and community access. Theresa lives in a compact 2-bedroom flat which can easily be cleaned in approximately 2 hours per week, but this service was arranged for a 4 hour clean per week. This used funds which could have been directed to speech therapy – a treatment Theresa had not received for over ten years.

When self-management of some funds in Theresa's NDIS plan was approved, the support coordination budget was cut on the basis that my unpaid support would supplement the paid support coordination. However, three days later my aunt rang me to insist I ask for a review of the plan saying she no longer wanted self-managed funds and only wanted the paid support coordinator to assist her. She said the activities she had intended to undertake with her self-managed funds were no longer important to her and she preferred the old arrangement.

I convinced Theresa to maintain the arrangement which gave her more flexibility in her NDIS plan but I was shocked the support coordinator and worker who speaks Theresa's first language had no scruples in trying to convince their client in something that was not in her best interest or expressed her will and preferences. In fact, Theresa had yearned about these activities for several years which had previously been included in her Victorian Independent Support Package (ISP).

The only people who benefitted from the NDIS funds being managed by the Agency or an intermediary was the support coordinator/support worker organisation. That their livelihoods were at stake could have impacted

on Theresa's immediate access to supports, however, in what other sphere or sector do service providers attempt to control the funds of their clients to the detriment of their client?

Input from her family was a safeguard against unethical and predatory behaviour designed to maintain the viability of the service based on deceit, not good customer service.

QUESTION 19. What impacts would stricter conflict of interest requirements have on NDIS participants and the NDIS market?

It would be remiss to overlook the fact that imposing stricter conflict of interest requirements on support coordinators is likely to result in a thin(ner) market in support coordinators in the short term. However, in the long term stricter requirements will uphold the integrity of the community-funded Scheme which is intended to lead to fuller inclusion and participation of people with disability and their carers in a variety of spheres such as employment, education, leadership and policy making. This result will be achieved without taking ethical shortcuts and reinforcing the low expectations people with disability and carers have endured previously. It will signal to the market and community that people with disability should expect the same standards as others in the community.

What was your role in obtaining a National Disability Insurance Scheme plan?

"Co-ordinating the entire thing, including hundreds of hours of meetings and preparing documents. I then had to put dozens of hours into setting the package up when we finally received it, including negotiating a dispute between services who got in a wrangle about the support they were providing to my brother."

Carer survey respondent

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This submission was prepared
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Rainbow Tick

Quality Innovation Performance
ACCREDITED

Carers Victoria acknowledges the traditional owners of this land and pays respect to elders both past and present.

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