

## **The illusion of 'Choice and Control'**

The difficulties for people with complex and challenging support needs to obtain adequate supports under the NDIS

**Accessible edition**

## **Acknowledgement of Country**

The Office of the Public Advocate (OPA) acknowledges Victoria's Aboriginal communities and their rich culture. OPA pays respect to their Ancestors, Elders and communities, who are the custodians of the land on which we work.

## **Client stories**

The client stories used to illustrate important points in this report have been de-identified. Names are fictitious.

## **Publication details**

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## Introduction from the Public Advocate

The Office of the Public Advocate's (OPA's) mission is to protect and promote the rights, interests and dignity of people with disability. It is a statutory office, independent of government and government services.

By virtue of its broad role within the Victorian disability, justice, mental health and health sectors, the office's work increasingly intersects with the National Disability Insurance Scheme (NDIS) as it rolls out across the state and country.

Through the interactions of OPA's Advocate Guardian and Community Visitors programs with the NDIS, the office has identified and developed a unique understanding of transitional and systemic issues which are creating significant hardship for many of OPA's clients.

OPA was moved to prepare this report after witnessing the significant human impact and harm experienced by clients when they receive inadequate supports under the NDIS. The costs to them for this failure, and to all of us, have been enormous.

The report draws heavily on case studies. We begin by looking at Robert's situation, which illustrates the human impact of inadequate support provision, the damaging interplay between different service systems, and the reality of an uncertain future. Elements and themes in Robert's story are mirrored in the eleven client stories contained in the Appendix which are drawn on throughout the report.

The report examines four key areas in which particular challenges are faced: access, planning, obtaining service providers, and accessing and retaining suitable accommodation.

The conclusion carries with it a warning; that these issues will remain and potentially escalate in scale and impact as full NDIS rollout is achieved unless significant and effective actions are taken immediately to ensure the NDIS delivers the intended transformational benefits for all people with disability.

Colleen Pearce

Public Advocate

## Executive summary

The NDIS is a tremendous reform which has the potential to empower and transform the lives of people with disability, their families and carers.

In many cases, the NDIS is delivering real benefits. However, as the NDIS is progressively rolled out across Victoria, it is becoming apparent that a large number of OPA's clients with complex and challenging support needs are not seeing the benefits that the scheme is intended to deliver.

The people experiencing the greatest difficulties under the NDIS typically:

- have multiple and/or severe disabilities requiring various forms of support, often compounded by experiences of trauma
- experience issues with interpersonal engagement, such that they have limited family support and/or are unable to live with others
- engage in challenging behaviours that can put themselves or others at risk of harm
- are or have been engaged in multiple government service systems
- have a history (or are at risk) of unstable accommodation, homelessness and/ or periods in detention in the criminal justice and/or mental health systems and, as a consequence of the above
- have exhausted (or are at risk of exhausting) service providers and workers.

While perhaps not typical of the average NDIS participant, many of OPA's clients fall within this cohort, as these factors often contribute to a need for guardianship.

Guardians advocate for and make decisions in the person's best interests within the scope of their appointment, which, in the NDIS context, may include decisions relating to access to services, accommodation and health care.

The Public Advocate may be appointed by the Victorian Civil and Administrative Tribunal (VCAT) as guardian for a person under the Guardianship and Administration Act 1986 (Vic) where the person has a disability that affects their capacity to make reasonable judgments about matters relating to their circumstances, there is a need to make a decision and there is no other suitable person to accept appointment as guardian.

This report draws heavily on the experience of twelve OPA clients.<sup>1</sup> One story appears following the recommendations, with the remaining stories included in the Appendix. All stories have been deidentified and pseudonyms used throughout.

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<sup>1</sup> While the report focuses on 12 clients, as at 30 June 2018, the Public Advocate is guardian for 84 NDIS participants.

As the client stories in this report demonstrate, people in this cohort experience many challenges in obtaining adequate supports under the NDIS, including:

- becoming NDIS participants at the earliest possible opportunity
- ensuring plans are adequate for their support needs from the outset
- engaging and retaining suitable service providers
- accessing and retaining suitable accommodation.

These challenges can have detrimental, sometimes devastating, consequences for the person.

In many instances, delayed or inadequate provision of supports and poor quality of services leads to avoidable detention and other infringements on an individual's human rights, and significantly compromises their ability to achieve their chosen life goals.

Many of these issues are not new; they have been highlighted by OPA, various inquiry bodies and other advocates for people with disability since the NDIS commenced rolling out. It is well-accepted by everyone, including the National Disability Insurance Agency (NDIA), that more work needs to be done to improve the implementation and operation of the NDIS.

However, system improvements to date have done little to fix the root cause of these issues and, like others, OPA wants to see action from the NDIA and Australian and Victorian governments to resolve these problems as a matter of urgency.

This report makes fifteen recommendations to improve system, service and operational issues to ensure the scheme delivers the intended transformational benefits for all people with disability.

## Recommendations

To better ensure that people with complex and challenging support needs receive adequate supports under the NDIS, OPA makes the following recommendations.

### Recommendation 1

The NDIA should finalise, pilot and roll out the proposed Complex Needs Pathway as soon as possible. Evaluation of the pathway must be outcomes-based and directly informed by the experiences of participants. The evaluation report should be a public document.

### Recommendation 2

All services which interact with people with disability, including all places of detention such as prisons and mental health services, should adopt protocols to identify whether people entering their service are NDIS participants or potentially eligible to be so, and to facilitate access requests at the earliest opportunity.

### Recommendation 3

The NDIA should urgently undertake the planning and consultation required to implement the McKinsey & Company Independent Pricing Review recommendations relevant to the pricing of supports for people with complex needs.

### Recommendation 4

The NDIA should enable contingency funding to be immediately accessible when crises arise. This approach would require designated liaison and emergency contact points and procedures within the NDIA (or authorised agencies) which are responsive during and outside of business hours.

### Recommendation 5

The NDIA should provide clear breakdowns and descriptions of the specific supports to be provided under each line item in participant plans. Where the amount of funding is significant, more detailed breakdowns should be provided.

### Recommendation 6

The NDIA should provide written reasons on request from a participant or person acting on their behalf regarding discrepancies between requested and approved supports.

### Recommendation 7

The Complex Needs Pathway should incorporate a range of safeguards regarding plan implementation. These should include a requirement for support coordinators to provide regular, periodic implementation reports to the person, the NDIA and, where applicable, the person's plan nominee and/or guardian. As well as detailing funds expended, such reports should incorporate participant views and feedback and address outcomes and progress towards goals.

## Recommendation 8

The NDIA should publish, consult on and implement its Maintaining Critical Supports and Immediate Support Response policy and framework as a matter of urgency. This policy and framework should ensure that:

- multiple designated providers of last resort are clearly identified
- providers of last resort are adequately resourced to enable them to respond immediately in situations of market failure which includes having staff available on short notice
- the providers and their staff have specialised experience, skill and expertise that are relevant to the specific needs of participants
- clear procedures exist to guide planners, local area coordinators and support coordinators when the need arises for a provider of last resort to provide any approved support (not just 'critical' supports)
- participant plans have built-in flexibility for situations in which a provider of last resort is required, including the ability to access contingency funding
- as soon as possible, participants are transitioned back to support outside provider of last resort arrangements
- provider of last resort mechanisms continue to exist beyond full rollout of the NDIS (and are not just a temporary or artificial market artefact during transition).

## Recommendation 9

The NDIA and Australian and Victorian Governments should publicly clarify who is responsible for ensuring that individual participants receive their funded supports. This responsibility must continue to be clear once the NDIS is fully rolled out.

## Recommendation 10

The NDIA should provide direct assistance to support coordinators who are struggling to navigate thin markets and support people with complex needs.

## Recommendation 11

The Victorian Department of Health and Human Services should:

- continue to operate its Intensive Support Team beyond full rollout of the NDIS
- provide ongoing case management for participants with complex and challenging support needs where this is required
- be prepared to act as support coordinator of last resort.

## **Recommendation 12**

The NDIA, in conjunction with the Australian and Victorian Governments, should adjust market levers and policies (including the pricing framework) to stimulate and ensure the existence of sufficient numbers and diversity of crisis accommodation providers, and should also ensure that sufficient funds are provided so that Specialist Disability Accommodation provision is able to meet existing and future demand.

## **Recommendation 13**

The NDIA should commission the provision of crisis and respite accommodation for participants who need accommodation at short notice.

## **Recommendation 14**

The NDIA's Maintaining Critical Supports and Immediate Support Response policy and framework should specifically address and provide guidance in relation to Specialist Disability Accommodation and crisis accommodation providers of last resort. The framework should include a vacancy management strategy for providers to prioritise clients with the most urgent need.

## **Recommendation 15**

The Australian and Victorian Governments should enact legislative and other safeguards to provide security of tenure and other rights protections for all forms of accommodation used by NDIS participants, including Specialist Disability Accommodation.

## Robert's story

Robert is a middle-aged man who enjoys cooking, going to the library, going out for a coffee and spending time with family members.

He has been diagnosed with autism spectrum disorder, schizophrenia, various personality disorders and an intellectual disability secondary to a significant brain injury he sustained in a car accident as a child. He has a long history of self-harm and suicidal behaviour, as well as childhood trauma and abuse. He also has a history of offending behaviour and involvement in the criminal justice system. Over the years, he has been involved in multiple service systems including child protection, mental health, disability support, forensic disability, corrections and housing services.

Robert became an NDIS participant by chance after he randomly presented to a disability service provider while looking for a different type of service; no-one involved in supporting him had assisted him to engage with the NDIS. Robert's initial NDIS plan was around \$400,000, with 92 per cent for core supports.

Prior to becoming an NDIS participant, Robert had been living in a two-bedroom Office of Housing property with active daily supports and sleepover support at night provided by a support agency. This model, initially funded through a DHHS Individual Support Package (ISP), was the longest sustained working model of support which Robert had experienced, and he still speaks positively about this time.

However, the transition from being supported by DHHS to the NDIS was poorly managed and Robert was required to relinquish his property as part of it. He was then allocated a one-bedroom Office of Housing property which did not meet his needs, and he did not have a housing manager to support him. He was, consequently, evicted from the property. After a period of time in a motel, Robert then moved into DHHS shared supported accommodation, but, after a short time, ended up being evicted from this property as well.

Robert's second NDIS plan was approved shortly after this eviction. It was smaller than the first, with a 37 per cent decrease in core support funding. OPA was appointed as Robert's guardian a few months later to make decisions regarding accommodation and access to services.

Since becoming homeless, Robert has moved between motels, at least seven or eight in the four months since OPA has been involved. He is often asked to leave after causing property damage or making unwarranted calls to emergency services. Motel accommodation is unstable, expensive and inappropriate for Robert, however, there are currently no other options available to him. His vulnerabilities, complex behavioural needs and limited frustration tolerance make it extremely difficult for him to live with others and, so, shared supported accommodation and SRS are not suitable. Private rental is also not an option due to his housing history and complex needs.

Robert's guardian and support coordinator have been advocating assertively to DHHS for an Office of Housing property for him. DHHS has said that Robert must exhaust crisis accommodation services first, however most crisis accommodation and homelessness services have advised that Robert is either ineligible or unsuitable for their services. DHHS has still not confirmed if Robert is on the waiting list for housing, and has recently asked his guardian to provide a letter outlining the human rights implications of his current situation before they will give further consideration to accommodating him.

Meanwhile, Robert continues to engage in chaotic, high-risk behaviour and regularly presents to police stations, emergency departments and mental health services, sometimes multiple times a day, in situational crises.

He has also incurred multiple, relatively minor criminal charges, often associated with him inappropriately contacting emergency services. He has been described as 'institutionalised' and his behaviours appear to be intended to elicit admission to mental health services or prison, which provide him with a form of security. Robert's local mental health service considers his behaviour to be personality or disability-driven and has noted that prolonged stays in mental health units escalate his behaviour. As a result, they refuse to provide ongoing services and, instead, refer his support back to other service systems. The [REDACTED] has advised that it is ill-equipped to adequately support Robert but its attempts to prevail on the mental health service system to assist have been unsuccessful. Accordingly, a referral was recently made to a mental health support service outside the public mental health system to obtain support for counselling, psychology and housing, but this referral has not yet been accepted.

Recognising that the supports funded under Robert's second NDIS plan were inadequate, a review was conducted three months after it was made. The new, six-month plan provides a similar quantum pro rata to his first plan, including funding for high intensity assistance with self-care from 6am to 12am each day, with sleepover support from 12am to 6am, as well as some specialist behavioural intervention and five-to-six hours of specialist support coordination a week. This recognises the complexity in his situation and the need for better coordination of supports to ensure that his plan is fully implemented and responsive to his needs.

However, Robert is onto his third support coordinator in four months. The first one quit after Robert became highly distressed while visiting their office and damaged some property. Robert's guardian terminated the service agreement with the second support coordinator, who had been recommended by the NDIA planner, as a result of concerns raised about their conduct and quality of service by Robert, his support provider and the motel he was then staying at. That support coordinator, who was employed by an interstate-based service, told the guardian that they were happy to relinquish the role as they felt inadequately supported by their organisation to perform it. Thankfully, the third support coordinator is far more engaged.

The disruptions caused by these changes in support coordination have impeded the search for ongoing, stable housing for Robert. Robert's transience has, in turn, made implementing the supports funded under his NDIS plan, and actually realising their intended benefits, practically impossible. There is an agreement for Robert's support provider, which was engaged a few months after he became homeless, to provide him with five hours a day of community participation and daily living support. However, on most days, Robert will not engage with them due to his mental health and accommodation issues. It is unclear how long this support provider will be able to continue their flexible and supportive approach to providing services to Robert if his situation does not stabilise soon.

## Challenges to obtaining adequate supports

### Becoming an NDIS participant at the earliest possible opportunity

#### Themes and findings

Many people with complex and challenging support needs are not aware of the NDIS and/or do not have the knowledge, skills and resources to independently initiate access to it.<sup>2</sup> A small number are reluctant to engage with the NDIS due to not identifying with the disability label or accepting they need supports. The vast majority of people in this cohort are, therefore, dependent on others to inform them about the NDIS and support them to make an access request. While Robert stumbled into making an NDIS access request by chance, access requests for all other clients in this report were initiated by their guardian, advocate or existing service provider.

As people with complex and challenging support needs are generally already known to and involved in at least one service system (such as justice, mental health, disability, housing and child protection) and have one or more existing service providers, there should be no reason why they cannot be supported to make an NDIS access request at the earliest possible opportunity. In fact, most people in this cohort would be eligible for consideration for early entry into the NDIS (ahead of the scheduled rollout for their catchment). However, of this group of clients, James was the only early entry participant and that was in the context of public and political attention, while Con, Oliver and Mohamed each experienced significant delays in becoming NDIS participants after they became eligible, despite being held in extended mental health detention pending the availability of appropriate supports.

Given this, it is concerning that service providers (including detention facilities which have complete control over the person) are not always facilitating access requests at the earliest possible opportunity for the people they are supporting or responsible for. In some cases, an access request is only made after a guardian has been appointed. Furthermore, around half of the clients featured in this report had previously received assistance during a police interview from OPA's Independent Third Person (ITP) Program,<sup>3</sup> which could have provided another opportunity for identification of, and advocacy around, their unmet support needs. However, despite OPA's past recommendations,<sup>4</sup> the ITP role remains limited and they are unable to undertake such advocacy.

Even so, once a person becomes an NDIS participant, there is evidence of significant delays in them obtaining an approved NDIS plan. For instance, Oliver's planning meeting did not take place until six months after he became a participant; Samir and Sue did not have their plans approved until six months after they became participants; and Yasmin did not have her plan approved until seven months after she became a participant. Given Oliver, Samir and Sue were being detained pending appropriate supports at the time, and Yasmin's care arrangements had broken down or were fragile at the very least, these delays are contrary to the NDIS operational guidelines for

<sup>2</sup> Issues with NDIS access and pre-planning are discussed in greater detail in Office of the Public Advocate, Submission No 82 to Joint Standing Committee on the NDIS, Parliament of Australia, Inquiry into Market Readiness, March 2018, from 6 ('OPA, Submission to Inquiry into Market Readiness').

<sup>3</sup> ITPs attend police interviews for adults and young people with cognitive impairment to facilitate communication and provide other supports to ensure they are not disadvantaged during the interview process.

<sup>4</sup> A key recommendation contained in the Office of the Public Advocate's report *Breaking the Cycle: Using Advocacy-Based Referrals to Assist People with Disabilities in the Criminal Justice System* (2012), was that, subject to OPA securing appropriate funding, the ITP Program should develop an advocacy and referral scheme for clients who have had, or who are clearly at risk of having, repeat contact with crime: at 8.

preparing plans, which state that the NDIA will prioritise preparing plans immediately or within a matter of weeks in such circumstances.<sup>5</sup>

## Consequences

The consequences of delayed entry to the NDIS and getting an NDIS plan in place are that people are missing out on the additional supports and other benefits intended to be delivered by NDIS. As explained further in the sections below, delays in accessing appropriate supports may also result in people entering or remaining in detention due to the risks arising from unmet support needs and/or cycling through unstable and inappropriate forms of accommodation, at tremendous human cost.

Delayed entry to the NDIS is further problematic because the Victorian Department of Health and Human Services' Disability Client Services (DHHS) is progressively withdrawing its services and funding as the NDIS rolls out across the state, which will leave people who have not transitioned without, or with reduced, supports.

## Solutions and recommendations

### *What's already happening?*

DHHS has established a Supported Access Team that works with service providers to provide intensive support to existing DHHS clients who are difficult to engage, have complex needs or are struggling to access the NDIS.<sup>6</sup>

In response to a need arising during transition, DHHS also established an Intensive Support Team (IST) to support existing clients with more complex needs who may require a longer handover period by facilitating a joint planning approach involving the NDIA planner and DHHS case manager or a member of the IST.<sup>7</sup>

OPA supports these initiatives and has experienced positive outcomes as a result of their engagement in some cases. However, it is unclear whether these teams will continue once the NDIS has rolled out in full.

In February 2018, the NDIA released an encouraging report outlining a 'new participant pathway' for interacting with the NDIS, which includes some features to improve access and engagement with the NDIS.<sup>8</sup> An initial pilot has commenced. This report also outlines an intention to create tailored participant pathways for specific populations groups who are recognised as needing additional help to navigate the NDIS. The proposed 'Complex Needs Pathway' will support people with complex needs who need additional support because of:

- "Involvement in other government service systems, in particular health, child protection, mental health and justice;
- Interaction with multiple government services or multiple community supports;
- Multiple diagnosis/clinical complexity;
- Insufficient support to assist with decision making, due to factors such as minimal or no informal supports, or a parent or carer with disability;

<sup>5</sup> NDIA, Operational Guidelines: Planning, NDIS

<sup>6</sup> Department of Health and Human Services (Vic), Tailored support for Victorian clients to access NDIS supports: Intensive Support Team, Supported Access Team (2017) 2 ('DHHS, Tailored support for Victorian clients to access NDIS supports').

<sup>7</sup> Ibid 1.

<sup>8</sup> NDIA, Improving the NDIS Participant and Provider Experience (2018) ('NDIA, Improving the NDIS Participant and Provider Experience').

- Complex behavioural support needs; and
- An immediate unmet need for support or a crisis situation”.<sup>9</sup>

The report proposes that the Complex Needs Pathway will include “warm transfers from states and territories or existing service providers, and their involvement, led by regional delegates, in preparing for [NDIS] access”<sup>10</sup> (plus other proposed features, discussed later in the report).

OPA understands that a pilot of the Complex Needs Pathway was carried out the first half of 2018, however OPA did not have any client interaction with the pilot. OPA understands a second pilot will commence in the second half of 2018. The implementation of the Complex Needs Pathway, on which OPA was consulted, is critical to supporting people with complex needs to successfully transition into, and through, the NDIS pathway.

The NDIA’s Hard to Reach Strategy, which has been under development at least since September 2017,<sup>11</sup> is due to be published in 2018 and will be aligned with the Complex Needs Pathway.<sup>12</sup> The NDIA has apparently also established a “unit to respond to complex cases including those involving health interfaces”.<sup>13</sup>

### **What else is required?**

OPA has repeatedly identified the need for assured government funding for advocacy services outside of the NDIS to support people to make timely access requests,<sup>14</sup> and reiterates this call.

There needs to be further work done to address the service and system fragmentation between the NDIS and mainstream services. OPA agrees with the Joint Standing Committee on the NDIS that:

*“[W]hilst interactions between the NDIS and mainstream services are guided by the Principles agreed by COAG, they are subject to interpretation and lack clarity. This is resulting in boundary issues and funding disputes, which can lead to reduced access or no access to services for both NDIS Participants and people with disability not eligible for the NDIS.”<sup>15</sup>*

In addition, OPA makes the following key recommendations to better ensure that potentially eligible people are supported to become NDIS participants at the earliest possible opportunity.

<sup>9</sup> Ibid 27.

<sup>10</sup> Ibid.

<sup>11</sup> Mark Rosser, NDIA, *The NDIS and Homelessness: Council to Homeless Persons* (2017).

<sup>12</sup> Australian Government, *Response to Joint Standing Committee on the NDIS*, Parliament of Australia, *Transitional Arrangements for the NDIS*, June 2018, 11 (‘Australian Government, Response to Inquiry into Transitional Arrangements for the NDIS’).

<sup>13</sup> Ibid 4.

<sup>14</sup> See, eg, Office of the Public Advocate, *Submission No 7 to Joint Standing Committee on the NDIS*, Parliament of Australia, *Inquiry into the Provision of Services Under the NDIS for People with Psychosocial Disabilities Related to a Mental Health Condition*, February 2017, 3-4 (recommendations 9 and 15); OPA, *Submission to Inquiry into Market Readiness*, above n 2, 2 (recommendation 3).

<sup>15</sup> Joint Standing Committee on the NDIS, Parliament of Australia, *Transitional Arrangements for the NDIS* (2018) ix. The Principles to Determine the Responsibilities of the NDIS and Other Service Systems are used to determine the service funding and delivery responsibilities of the NDIS vis-à-vis other service systems. OPA has previously called for the Principles to be reviewed to ensure they address key interface problems that have arisen since full scheme roll out commenced: for further detail see OPA, *Submission to Inquiry into Market Readiness*, above n 2. The Principles are contained in the Bilateral Agreements signed by the Commonwealth and individual states and territories (for eg, *Bilateral Agreement between the Commonwealth and Victoria: Transition to a National Disability Insurance Scheme*, sch I: Arrangements for the Interface between the NDIS and Mainstream Services in Transition, attachment A: Principles to Determine the Responsibilities of the NDIS and Other Service Systems (November 2015).

## **Recommendation 1**

The NDIA should finalise, pilot and roll out the proposed Complex Needs Pathway as soon as possible. Evaluation of the pathway must be outcomes-based and directly informed by the experiences of participants. The evaluation report should be a public document.

## **Recommendation 2**

All services which interact with people with disability, including all places of detention such as prisons and mental health services, should adopt protocols to identify whether people entering their service are NDIS participants or potentially eligible to be so, and to facilitate access requests at the earliest opportunity.

## **Ensuring plans are adequate in scope from the outset**

### **Themes and findings**

#### ***Issues with NDIA planning processes and documents***

It is clear that NDIS participants and their supporters encounter NDIA planners of extremely varied experience, skill and dedication, which has a flow-on effect on the planning process and quality of the resultant plans.

The people in the complex cohort have multiple, significant disabilities which, along with past experience of trauma, have a compounding impact on their functional capacity and support needs. It is notable that autism diagnoses or traits feature strongly (see Yasmin, Dylan, David, Con, Robert, Sue and Ryan). Diagnostic uncertainty also features, with many people described as having unique and complex presentations. Quite often, these people have straddled, and been bounced back and forth between, the mental health and disability service systems over many years, with neither system wanting to accept responsibility for their support (see Sue, Michael, Con and Robert).

For this cohort, it is essential that planners take sufficient time to engage with the person and accept advice from people who have worked with them and understand their unique and complex support needs. However, it appears that there is insufficient skill, expertise and assessment support held in-house by many NDIS planners. Many planners do not, at least initially, understand participant readiness, appreciate the complexity of people's situations or accept pertinent advice. Phone planning meetings in this context, or even a single planning meeting rather than ongoing dialogue, are likely to lead to inadequate plans. OPA has found it particularly difficult to get the NDIA to meet with participants and engage in effective planning processes for them when they are in custody, especially if they have no fixed release date.<sup>16</sup> Some OPA guardians have also noticed a shift during the course of the NDIS rollout from NDIA planners initially taking a principled stance of only talking directly with the person with disability and not their service providers and house coordinators to, now, often bypassing the person in the interests of efficiency and a perception that the professionals 'know best'. OPA's experience is that better outcomes are more likely to be achieved for people in this cohort when a guardian or other advocate is present in planning meetings to represent their rights and wishes.

A further challenge to obtaining an adequate plan is that it is sometimes difficult to get the appropriate assessments and evidence to justify the scale of funding that is required. This is especially difficult when the person is in detention because their adaptive and functional behaviour

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<sup>16</sup> Australians for Disability Justice understands that the NDIA's current practice is to only engage in community-based support planning once the person has a known release date and is within six months of that date: Submission No 121 to Joint Standing Committee on the NDIS, Parliament of Australia, Inquiry into Market Readiness, March 2017, 15 ('ADJ, Submission to Inquiry into Market Readiness').

in the community cannot be assessed in situ. This issue caused delays for both Sue and Samir. In the latter case, the issue was compounded by the mental health service failing to cooperate.

The items approved in NDIS plans are described in such brief and vague terms that it is often hard for someone to pick up a plan and understand what has actually been funded. For instance, Sue's current plan provides well over \$1 million in 'core supports', with the breakdown simply stating:

- "Funding for low risk daily adaptive equipment
- [A]ssistance in individual living arrangement for person with complex needs (x 1)
- Funding for recreational, social and community activities of your choice."

Similarly, Dylan's guardian remains unclear about what has actually been approved in relation to his accommodation: they initially thought that funding for 'robust build' Supported Disability Accommodation had been approved but only a small quantum for "home modifications" appears in his plan and, while there seems to be a verbal agreement that a much more substantial quantum will be provided for home modifications, this is not recorded in the plan. The lack of detail in NDIS plans makes it particularly difficult for any guardians, support coordinators or others coming on board after the plan has been made to make sense of and help implement them, which in turn makes it harder to produce better, consistent outcomes for participants.

Many OPA guardians noted with frustration the lack of clarity regarding who within the NDIA actually makes the decision regarding plan approval. In some cases, such as with Yasmin's and Oliver's initial plans, they experienced positive planning meetings where the planner seemed to 'get' what was required, but then the approved plan came back inexplicably smaller.

In Yasmin's case, it was [REDACTED] (64 per cent) smaller than the quotes provided. In another matter, an OPA client's approved plan was only a quarter of what had been discussed at the planning meeting. This lack of decision-making transparency, which is compounded by the failure of the decision-maker to give clear reasons for any refusals or discrepancies in funding,<sup>17</sup> makes it difficult to understand the basis of decisions and to advocate effectively on the person's behalf.

Finally, poor communication generally from the NDIA, such as failure to provide information or explanations, respond to communications, provide copies of plans, schedule plan review meetings, provide notice of meetings and attend meetings, was apparent in Yasmin's, Sue's, Oliver's, James' and Brian's stories. In some instances, a change of NDIA planner significantly improved the situation.

### ***Issues with the scope of funding approved***

Many people with complex and challenging support needs, at least initially, received approved NDIS plans which were clearly inadequate for their ongoing support needs. For instance, Michael and Oliver received [REDACTED] respectively in their initial plans, despite each being in secure, long-term mental health detention and needing community accommodation and high levels of transition support.

In some cases, people received less funding and, consequently, fewer services under the NDIS than they did under their DHHS ISP. For instance, Yasmin's first plan did not cover the 24-hour support model she had previously had, and Brian had a shortfall of over [REDACTED] worth of clinical services. Ryan also received a succession of NDIS plans which did not fully meet his needs and, when more significant plans were approved, the NDIA made clear its expectation that the

<sup>17</sup> The Commonwealth Ombudsman found that the NDIA's letter template does not provide participants with "a clear or sufficiently detailed explanation of the reasons for their decision": Administration of Reviews under the National Disability Insurance Scheme Act 2013: Report on the National Disability Insurance Agency's Handling of Reviews, Report No 3 (2018) 9 ('Commonwealth Ombudsman, Report on NDIA's Handling of Reviews').

increased funding was temporary and the support models would have to be scaled back within a few months.

These examples are likely due to failures of NDIA planners to accept advice around their complex needs, as well as a perceived push to keep NDIS costs low and sustainable. In other cases, however, such as Sue's and Samir's, the initial plan was kept small with a focus on getting a support coordinator in place to prepare and make the case for a subsequent, more sizeable plan.

There are a number of supports types which the NDIA seems particularly reluctant to approve, even though they often seem to be necessary for people in this cohort:

- Despite entrenched accommodation issues frequently featuring in these case stories, funding for SDA remains rare and limited, along with funding for home modifications and supports to maintain tenancies (see further detail below).
- Even though the interface principles<sup>18</sup> acknowledge that the NDIA bears responsibility for a participant's disability support needs while they are detained in or transitioning from prison or other places of detention, such supports are not often provided in practice. For example, Sue was in custody for 17 months before she received an adequate NDIS plan and, consequently, despite her extreme disability-related dysfunction, did not receive any tailored disability support in prison until near the end of her period in remand, and the NDIA was reluctant to allow Dylan to use his core support funding for supports delivered to him within the secure extended care unit (SECU). OPA has also found that, where a person has had contact with the criminal justice system or is on a civil risk-management order, the NDIA is sometimes inappropriately categorising what should be seen as disability-related supports as "offence specific interventions" which, under the interface principles, "other parties and systems" are responsible for funding. However, these other parties cannot be relied on to actually provide these supports.<sup>19</sup> OPA's experience in this regard echoes findings of the Joint Standing Committee on the NDIS.<sup>20</sup>

<sup>18</sup> Bilateral Agreement between the Commonwealth and Victoria: Transition to a National Disability Insurance Scheme, sch I: Arrangements for the Interface between the NDIS and Mainstream Services in Transition, attachment A: Principles to Determine the Responsibilities of the NDIS and Other Service Systems (November 2015) 24. See also National Disability Insurance Scheme (Support for Participants) Rules 2013 (Cth) rr 7.23-7.25.

<sup>19</sup> [S]ome of the responsibilities accorded to the justice system in the COAG principles have seldom been available in the pre-NDIS environment; for example, "specific interventions to reduce criminal behaviours" and intensive case coordination – both of which are attributed to mainstream services – are not currently provided by the justice system and it is unlikely that they will be under the NDIS: Office of the Public Advocate, Submission No 46 to Productivity Commission, NDIS Costs Study, 24 March 2017, 2. This is discussed further in Office of the Public Advocate, Submission No 69 to Joint Standing Committee on the NDIS, Parliament of Australia, Inquiry into Transitional Arrangements for the NDIS, August 2017, from 19, and ADJ, Submission to Inquiry into Market Readiness, above n 16, 25.

<sup>20</sup> "[W]hilst interactions between the NDIS and mainstream services are guided by the Principles agreed by COAG, they are subject to interpretation and lack clarity. This is resulting in boundary issues and funding disputes, which can lead to reduced access or no access to services for both NDIS Participants and people with disability not eligible for the NDIS. Additionally, the committee found that the current transition of Commonwealth, state and territory programs to the NDIS is contributing to emerging service gaps and the lack of clear delineation of funding responsibility between the NDIS and state and territory services": Joint Standing Committee on the NDIS, Parliament of Australia, Transitional Arrangements for the NDIS (2018) ix ('Joint Standing Committee, Transitional Arrangements for the NDIS').

- Many people in this cohort have large, multidisciplinary care teams and multiple service providers. However, the NDIA does not fund case management and does not always provide funding for care team communication, information sharing and training. For example, unlike under his ISP, there was no funding in Brian's NDIS plan for his psychologist to attend care team meetings or provide updated risk assessments. Similarly, unlike under her ISP, the following were not funded under Yasmin's plan:
  - any of the team of allied health professionals who had provided clinical leadership
  - regular meetings between her support providers
  - training and behaviour management support for her secondary support provider.

As can be seen in the stories in this report, many people with complex and challenging support needs do eventually have very large NDIS plans approved. However, obtaining approval for adequate, ongoing funding sometimes only occurs after significant external pressure is applied by a guardian, the media and/or a court, or following an often-predictable crisis. For instance:

- Michael's second plan was five times greater than his first plan.
- Sue's initial plan for around ████████ over 12 months was increased six months later to around ████████ over nine months, during which time considerable pressure had been applied by OPA and the court.
- Yasmin's initial plan represented only 64 per cent of the quotes for her existing supports. It was increased by 84 per cent pro rata (to over ████████ over four months) in her second plan. However, this only occurred after serious assaults on members of the public and multiple other crises.
- There was a 57 per cent pro rata increase (to around ████████ over six months) between Robert's second and third plans, but this was only approved after prolonged transience and multiple crisis presentations to emergency services.
- Ryan's plans were successively increased over time, with his third plan being 40 per cent pro rata more than his first plan and subsequent plans even greater, but at various points the NDIA made it clear they expected the level of support to be dropped down within a few months.

Often, these subsequent plans are approved for a shorter period to enable closer monitoring during anticipated changes in circumstances.

Consistent with the recent findings of the Commonwealth Ombudsman,<sup>21</sup> there are also often significant delays in getting a plan review to achieve these increased supports. For example:

- Yasmin's initial plan was known to be inadequate as soon as it was made but the review did not occur until 10 months later, by which time, multiple incidents had occurred and the lead support provider had pulled out.
- Despite repeated requests, no plan review was scheduled for Brian until the existing plan expired eight months later.

Finally, given the frequency with which high-risk and damaging crises occur for people in this cohort, it is problematic that there is limited access under the NDIS to fast and flexible contingency funding and service responses when a participant's needs fluctuate or when crises arise (including where a participant is in custody or their tenancy is in jeopardy – discussed later in the report). Having to wait months for a plan review during a crisis is simply not acceptable. As the Productivity

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<sup>21</sup> Commonwealth Ombudsman, Report on NDIA's Handling of Reviews, above n 17, 14.

Commission and Joint Standing Committee have both found, it also remains unclear whether the NDIS or state or territory governments are responsible for funding emergency supports for accommodation.<sup>22</sup>

## Consequences

Significant costs are incurred to the person, the NDIA, other service systems and the community as a result of the above planning issues and the inadequate scope of many initial plans. Failure to fund necessary supports and services, or delays in approving such funding, means that people will not receive the supports they need, which negatively impacts on their wellbeing and contributes to harmful crises occurring in their lives. When such crises do occur, there is no funding, time or personnel available to swiftly create a workable support model for a person with complex needs from scratch. As can be seen from stories such as Yasmin's, Ryan's, Dylan's and Robert's, inadequate supports may result in challenging or high-risk behaviours which lead to the withdrawal of services and/or accommodation, and/or entry into mental health or criminal justice detention, which could have been averted had the plan provided adequate funding from the outset. This is explored later in the report.

Failure to fund necessary supports in a timely manner also hinders people being released from criminal justice or mental health detention at the earliest opportunity, as they generally will not be released until such supports are in place. For example:

- Sue became an NDIS participant five months after she was remanded. It then took six months to get a small NDIS plan approved for support coordination and a further six months to get a full NDIS plan approved with the necessary supports. She ended up spending 17 months on remand until the provision of accommodation and supports enabled her release, and she experienced extreme distress and trauma as a result.
- Con was detained in a SECU for two and a half years, with most of that period being due to lack of suitable accommodation and supports. He was potentially eligible for the NDIS years prior to this admission and has been an NDIS participant for at least two years. However, the supports funded under his NDIS plans were described as "inappropriate" by his social worker.
- Samir has been detained in a secure mental health facility for three and a half years, so far, due to lack of suitable accommodation and supports, which is two years after the rollout of the NDIS to his area and one and a half years after he became an NDIS participant. His current NDIS plan still provides for little else beyond support coordination.
- Michael has been detained in a SECU for nine years, so far, due to lack of suitable accommodation and supports. He has been an NDIS participant for one year and has only just had a new plan approved with sufficient supports to enable his transition back to the community.

The consequences of prolonged detention are discussed later in the report.

Failure to make provision for care team communication and information-sharing within NDIS plans creates risk management and governance issues, which can be costly to the person and the community. For example, Yasmin's guardian was not aware that her NDIS plan did not provide for these until after she had seriously assaulted members of the public.

Similarly, Brian's psychologist advised that the failure to fund these in his plan has had a considerable impact on clinical governance and the holistic approach in his care, management, supervision and risk manageability, which compromises the team's ability to implement his mandated treatment and meet risk-reducing treatment goals.

<sup>22</sup> Productivity Commission, NDIS Costs, Study Report (2017) 250; Joint Standing Committee, Transitional Arrangements for the NDIS, above n 20, 35.

Other costs which are incurred as a result of inadequate plans are:

- time and resources spent on additional plan reviews which could have been avoided
- inefficiencies when service providers pull out and change regularly when operating in an inadequate funding environment
- people requiring more intensive (and expensive) supports to re-establish themselves after they have been allowed to fall into, or remain in inappropriate, harmful circumstances due to inadequate supports (as was the case for Sue and Ryan).

All of these human, financial and systems costs would be minimised if funding for all predictable, necessary supports was approved in people's NDIS plans from the outset. Seeking to keep initial plans minimal is, therefore, a false economy.<sup>23</sup>

A consequence of the brevity and vagueness of the descriptions of supports funded under a person's NDIS plan, especially where the quantum of funding is large, is that it is hard for anyone to oversee whether the plan is being implemented and the funding spent appropriately. People in this cohort are often poorly placed to monitor this themselves, and guardians are not always provided with a copy of the person's plan and do not have access to the NDIS portal to oversee how, and how much of, a person's funds have been spent.

The system relies on support coordinators, where they are involved, to oversee the implementation of plans and to provide an implementation report to the NDIA near the plan's expiry. However, given concerns have been raised about the performance of support coordinators (discussed further below), there needs to be further safeguards to ensure positive outcomes for participants.

It is noted that the NDIS Quality and Safeguarding Framework<sup>24</sup> and the NDIS Quality and Safeguards Commission will commence operating in Victoria on 1 July 2019, but it does not appear that these mechanisms will provide oversight of plan implementation or outcomes achieved. The role of the commission is discussed later in the report.

## Solutions and recommendations

### *What's already happening?*

In relation to planning processes, the NDIA advised the Commonwealth Ombudsman in November 2017 of a number of new and upcoming initiatives to improve participants' experience of the review process, including the implementation of a national team to address the outstanding backlog of review requests and a trial of 'Early Solutions Teams' in NSW which will:

- triage and acknowledge review requests for allocation
- identify alternatives to review (for example, a better explanation of decision or referral to a local area coordinator to explain or activate a plan)
- conduct 'light touch plan reviews'.<sup>25</sup>

<sup>23</sup> Studies have demonstrated the cost savings of providing timely and early intervention disability supports to people in the criminal justice system: see, eg, Ruth McCausland, Eileen Baldry, Sarah Johnson and Anna Cohen, *People with Mental Health Disorders and Cognitive Impairment in the Criminal Justice System: Cost-Benefit Analysis of Early Support and Diversion* (2013). The Productivity Commission also highlighted that early investment in NDIS supports will improve outcomes and minimise costs over the long term, even if that means spending more upfront, and urged that costs 'be considered from a long-term perspective': NDIS Costs, Study Report (2017) 71, 263.

<sup>24</sup> Department of Social Services (Cth), NDIS Quality and Safeguarding Framework (2016).

<sup>25</sup> Commonwealth Ombudsman, Report on NDIA's Handling of Reviews, above n 17, 3.

The NDIA is also changing its technology systems to enable straightforward corrections to a plan without the need for a full plan review. However, this is likely to be inadequate for the scope of changes many plans require.

As noted, the NDIA has recently released a report outlining a new participant pathway, which includes a commitment to face-to-face engagement for all NDIS plan development (provided this is the participant's preference), a consistent point of contact, improved communication and a stronger focus on the broader system of supports for people with disability.<sup>26</sup> These features are being piloted in two Victorian regions.<sup>27</sup> The NDIA has also committed to developing a tailored Complex Needs Pathway, which would include the following planning-related features:

- “planning conversations with participants and other stakeholders, led by agency planners with specialist skills, focused on ensuring a deep understanding of participant context and circumstances...
- continuous monitoring and evaluation of plan usage and outcomes, with the ability to make minor adjustments to supports and approaches to improve effectiveness; and
- support through the process by someone the participant trusts.”<sup>28</sup>

In May 2018, the Commonwealth Ombudsman made 20 recommendations to improve the NDIA's administration of reviews, including to amend the template letters to provide better reasons for decisions and to develop and publish key performance indicators or agreed service standards for the completion of plan reviews.<sup>29</sup> In response, the NDIA has stated it “accepts the merit of each of the recommendations, and has started determining the most practical ways to implement responses”.<sup>30</sup>

In relation to plan funding, the McKinsey & Company Independent Pricing Review made a number of recommendations relevant to the pricing of support for people with very complex needs, including that the NDIA:

- “develop a definition for complexity linked to the skills required to meet participant's needs, and use its specialised planning resources to classify what skills are required, and which participants require higher skilled support workers...
- add an additional tier to the high intensity loading [of 10 per cent] to allow a provider to recover the cost of a support worker with a higher level of skill than can be procured with the current high intensity loading [5.5 per cent]... which should also take into consideration the incremental ongoing training and development necessary for support workers serving very complex participants... [and]
- develop a consistent process for participants with extreme behaviours of concern that acknowledges the specialised needs of the participant cohort, and the environment providers operate in”.<sup>31</sup>

The NDIA gave in-principle support to the review's 25 recommendations in March 2018.<sup>32</sup> However, in April 2018, it advised that it had become apparent that the implementation of the

<sup>26</sup> NDIA, Improving the NDIS Participant and Provider Experience, above n 8, 4.

<sup>27</sup> Ibid 40.

<sup>28</sup> Ibid 27.

<sup>29</sup> Commonwealth Ombudsman, Report on NDIA's Handling of Reviews, above n 17, 17, 19 (recommendations 5 and 20b).

<sup>30</sup> Ibid 20.

<sup>31</sup> McKinsey & Company, Independent Pricing Review: National Disability Insurance Agency – Final Report (2018) 50, 51, 54 (recommendations 6, 7 and 8) ('McKinsey & Company, Independent Pricing Review').

<sup>32</sup> NDIA, [Independent Pricing Review, NDIS](#)

recommendations relating to complex supports “requires further detailed work or greater consultation... [and] will progressively be phased in”.<sup>33</sup>

OPA also understands that DHHS has acknowledged its continued role in disability justice services and plans to employ forensic disability support coordinators to provide the justice-related supports which the NDIS does not fund for people with disability on criminal justice orders.

### ***What else is required?***

OPA is encouraged by each of the developments noted above and supports the recommendations of the various reports. In particular, the introduction of the proposed Complex Needs Pathway, if done well, should assist in dealing with the identified planning and interface issues to a significant degree. Time dedicated to pre-planning preparation is also critical. It will be essential for NDIA planners to get to know each participant, listen more to the advice of experts and those who have experience supporting the participant, and adopt a long-term perspective by approving funding for all reasonable and necessary supports at the outset rather than trying to keep initial plans minimal. This includes ensuring that support coordination is adequately funded in plans to meet participants’ needs, and is not limited to a fixed period.

Where information is lacking or there are significant uncertainties or anticipated changes, the NDIA should approve a shorter-term plan. This should include funding for functional behaviour analysis and other assessments which are necessary to demonstrate what supports will be necessary and effective for the person. Making a shorter-term plan will ensure it will be reviewed again quickly so that funded supports remain appropriate for the participant’s changing needs, rather than having to request and wait for a plan review during the course of a 12-month plan. Providing more detailed information about planning discrepancies may lead to fewer plan reviews and may limit the number of appeals. Providing sufficient detail increases the capacity of people involved in the planning process to improve the next plan, facilitates better advocacy involvement and improves options to adequately support participants. OPA<sup>34</sup> and the Joint Standing Committee<sup>35</sup> have previously recommended that work be done to ensure that key boundary and interface problems, especially with the justice, health and mental health systems, are addressed in terms of demonstrable public outcomes. This work remains outstanding. In addressing boundary issues, it must be recognised that a clear demarcation and allocation of the complex needs of some people with disability between the different service systems may not be possible, or even desirable.

In addition, OPA makes the following key recommendations to better ensure that NDIS plans are adequate from the outset.

### **Recommendation 3**

The NDIA should urgently undertake the planning and consultation required to implement the McKinsey & Company Independent Pricing Review recommendations relevant to the pricing of supports for people with complex needs.

### **Recommendation 4**

The NDIA should enable contingency funding to be immediately accessible when crises arise. This approach would require designated liaison and emergency contact points and procedures within the NDIA (or authorised agencies) which are responsive during and outside of business hours.

<sup>33</sup> NDIA, Independent Pricing Review – Implementation Update, NDIS (‘NDIA, Independent Pricing Review – Implementation Update’).

<sup>34</sup> Office of the Public Advocate, Submission No 69 to Joint Standing Committee on the NDIS, Parliament of Australia, Inquiry into Transitional Arrangements for the NDIS, August 2017, 3 (recommendation 1) (‘OPA, Submission to Inquiry into Transitional Arrangements’).

<sup>35</sup> Joint Standing Committee, Transitional Arrangements for the NDIS, above n 20, xi (recommendation 1). Productivity Commission, NDIS Costs, Study Report (2017) from 268.

### **Recommendation 5**

The NDIA should provide clear breakdowns and descriptions of the specific supports to be provided under each line item in participant plans. Where the amount of funding is significant, more detailed breakdowns should be provided.

### **Recommendation 6**

The NDIA should provide written reasons on request from a participant or person acting on their behalf regarding discrepancies between requested and approved supports.

### **Recommendation 7**

The Complex Needs Pathway should incorporate a range of safeguards regarding plan implementation. These should include a requirement for support coordinators to provide regular, periodic implementation reports to the person, the NDIA and, where applicable, the person's plan nominee and/or guardian. As well as detailing funds expended, such reports should incorporate participant views and feedback and address outcomes and progress towards goals.

## **Engaging and retaining suitable service providers**

### **Themes and findings**

As noted above, many people with complex and challenging support needs end up with very large NDIS packages, regardless if it took some harmful periods and strenuous advocacy to get there. However, as is clear from many of the stories in this report, having access to considerable NDIS funding does not ensure that people receive the supports and services they need, and are entitled to, to achieve their goals.

The NDIS is premised on there being a marketplace of ready and willing service providers competing for business, and that NDIS participants will have choice and control in this market about who they contract with to provide them with supports. However, as highlighted by the Productivity Commission,<sup>36</sup> the NDIS' ambitious rollout schedule has meant that the market of NDIS providers is thin on the ground. This is especially true in regional areas.

For instance, Oliver had to change support coordinators because his existing one did not provide services in regional Victoria, and David's guardian made the decision to relocate him from regional Victoria to ██████████ because, after months of trying, they were unable to secure any service providers to support him in his region. The challenges for existing providers to successfully mature in the new NDIS market, and for new providers to enter the market, are discussed further in OPA's recent submission about NDIS market readiness.<sup>37</sup>

The Joint Standing Committee, the Productivity Commission and the McKinsey & Company review all found that the thin market problem is exacerbated for people with complex needs, with very challenging behaviour and/or in crisis.<sup>38</sup>

Despite the high levels of funding on offer through their NDIS plans, many service providers are unwilling to assist them because of the complexity, challenges and risks involved in meeting their needs. Accordingly, they decline referrals outright or withdraw services when problems arise.

<sup>36</sup> Productivity Commission, NDIS Costs, Study Report (2017) from 268 ('Productivity Commission, NDIS Costs').

<sup>37</sup> 37 OPA, Submission to Inquiry into Market Readiness, above n 2, from 12.

<sup>38</sup> Joint Standing Committee, Transitional Arrangements for the NDIS, above n 21, x; Productivity Commission, NDIS Costs, above n 36, 269; McKinsey & Company, Independent Pricing Review, above n 31, 5.

For instance:

- multiple, successive service providers withdrew from supporting Yasmin, Ryan and Dylan, citing business risk and occupational health and safety concerns, and it was challenging to recruit new providers each time.
- the service provider which had been supporting David under his ISP did not want to continue providing services to him under the NDIS, and no other local service was available or willing to assist him. As noted above, he eventually had to be relocated to Melbourne in order to secure a service provider.

Put bluntly, the people in this cohort are not an attractive business prospect for the private market.

These NDIS market issues are compounded by the absence of any designated service provider/s of last resort. Prior to the NDIS, DHHS accepted responsibility for supporting people with complex needs and could be relied on to provide supports and ensure a person did not become homeless even in challenging circumstances; it would have been too politically damaging for DHHS to attempt to withdraw all supports from a person when significant challenges arose. However, as the Joint Standing Committee found,<sup>39</sup> there is growing evidence of service providers ‘cherry picking’ the clients they want to provide services to under the NDIS.

Because they are operating a business, not all service providers demonstrate an ongoing commitment to their (potential) clients in the way that DHHS had to, and as private providers they have no responsibility to enter or continue contracts against their wishes. However, despite acknowledging these market issues, neither the NDIA, Australian nor Victorian governments have, so far, accepted responsibility for ensuring that funded supports are actually delivered to NDIS participants – there is currently a vacuum of responsibility. Accordingly, in the absence of any enforceable obligation against anybody, the nature of the NDIS market means that people in this cohort may experience very long periods of time with no supports or inadequate supports, despite having large NDIS packages at their disposal.

In many of these stories, it takes considerable effort and advocacy – and sometimes pressure from the courts or mass media (see Ryan’s and Sue’s stories) – to secure services. In Dylan’s case, having DHHS rather than a private provider as support coordinator has been crucial. While DHHS did respond to political pressure and moved Dylan from his supported accommodation to a motel without his guardian’s consent, which triggered an extended crisis period, his guardian believes that there is “no way” that the more positive results recently achieved would have been possible without DHHS being able to liaise internally with other parts of government, use its contacts and call in favours. However, achieving solutions through public pressure on a piecemeal basis fails to address the underlying systemic issues.

Given the challenges in engaging and maintaining service providers for people in this cohort, it is, therefore, concerning when DHHS withdraws its case management and other services from a person before they have a support coordinator in place. For instance, DHHS withdrew services within a week of David’s NDIS plan commencing, and they also withdrew before James had a support coordinator or any other services in place. Similarly, DHHS closed its file for Ryan when he first became an NDIS participant and, despite the ensuing crises and the support coordinator’s inability to engage service providers, it did not meaningfully re-engage until a year later in the context of considerable external pressure. The Joint Standing Committee found that “the transition to a market-based system combined with the transition of Commonwealth, state and territory programs have resulted in emerging service gaps in important areas, including advocacy, assertive outreach and support coordination”.<sup>40</sup>

<sup>39</sup> Joint Standing Committee, Transitional Arrangements for the NDIS, above n 20, 70.

<sup>40</sup> Ibid x.

Even where a support provider has been engaged, concerns have been raised about the quality of its services and practices in a number of cases. The Joint Standing Committee found that “the administrative burdens experienced by service providers, the inadequacy of NDIS pricing caps and disability workforce shortages are significant barriers to the delivery of NDIS services across all jurisdictions”.<sup>41</sup> This means that service providers often employ staff on a casual basis, struggle to recruit suitably qualified and experienced staff, and experience high workforce turnover. High turnover can mean that any funding for staff training in a person’s NDIS plan is already exhausted by the time new staff come on board. Furthermore, the thin market problem can also lead to non-preferred or inexperienced service providers being engaged to provide supports to this highly complex cohort because there are no other options.

Predictably, workers with limited training and experience will struggle to provide an effective, high quality service or be able to consistently implement positive behaviour supports in these circumstances. For example:

- The support provider engaged at short notice to support Dylan after the previous one pulled out was under-prepared to meet his complex support needs. Their practices caused Dylan further distress and he ended up removing himself from the property, and the support provider withdrew services after a very short time.
- An interim support provider was engaged for Yasmin during the search for a suitably experienced provider to take over her long-term support. The support workers lacked the confidence and skills to support her effectively, and their unsupported assumption that her behavioural presentation was psychotically driven, compromised their willingness and ability to implement recommended strategies. This resulted in multiple police call-outs and transports to hospital. Nevertheless, when it proved impossible to engage an experienced provider to deliver the required 24-hour support model, this interim support provider was kept on to provide the additional support hours.
- Ryan received poor quality supports from a succession of support providers, and was allegedly assaulted by a staff member of one (the provider was subsequently deregistered). When a more experienced support provider could not be engaged, there was no option but to re-engage a previous support provider, which had been unable to manage his support appropriately in the past, on an interim basis. Before the preferred support provider could commence, Ryan left his property unaccompanied twice and allegedly assaulted members of the public, leading to him being remanded in custody. Lack of stable and competent support was considered to have contributed to the conditions which led to this alleged offending.

It must be acknowledged that providing supports to people in this cohort is exceeding challenging and it is, therefore, pleasing there is evidence in some stories of particular support providers doing their utmost to provide dedicated, flexible and highly effective services.

### ***Support coordination***

The Productivity Commission recently reported that only 59 per cent of supports approved in NDIS plans in 2016-2017 were actually utilised.<sup>42</sup> It attributed this to insufficient supply of supports to meet demand, participants experiencing difficulties navigating the system, immature and thin

<sup>41</sup> Ibid ix. Similarly, the Productivity Commission found that the NDIA’s “approach to setting price caps to date has hindered market development by discouraging the provision of some disability supports. In some cases, it has led to poor participant outcomes, especially for those with complex needs”: Productivity Commission, NDIS Costs, above n 36, 55.

<sup>42</sup> Ibid 119. The NDIA’s actuarial modelling indicates that the utilisation rate may increase to 70% once all invoices are received.

markets limiting the help that participants can obtain, and some participants being unable to easily access information about how much of their supports are available.<sup>43</sup>

These barriers make effective support coordination<sup>44</sup> and specialist support coordination<sup>45</sup> vital for people with complex and challenging support needs to implement their plans.<sup>46</sup> However, as with other forms of support, it can be difficult for them to engage a suitable support coordinator. Delays in engaging a support coordinator can, in turn, lead to delays in implementing other forms of support and, thus, gain value from their plan. For instance:

- It took months to engage a support coordinator for Sue after her NDIS plan was approved; no provider wanted to take on the role due to the complexity of her situation. This delayed the preparation of a proposal for a second NDIS plan with the full range of supports that she required in order to be released from prison.
- The agency which had been supporting James under his ISP would not agree to provide services to him under the NDIS, and it took four months after his NDIS plan was approved to find a willing support coordinator. None of his other support funds were spent during this delay.
- Oliver has only just commenced receiving support coordination services more than three months into his NDIS plan, and no other supports have been implemented in that time.

As with support providers, some of the stories raise questions about whether particular support coordinators are competent, working effectively and/or are adequately funded to fulfil their role, which again can lead to delays in obtaining funding for and implementing other necessary supports. For example:

- Yasmin's initial support coordinator was highly avoidant and ineffective, which led to a ten-month delay in organising a review of her clearly inadequate plan. A new support coordinator was eventually allocated after a complaint was made to their manager.
- Samir's support coordinator was specifically engaged to gather evidence and develop a proposal for ongoing supports within three months. One year later, with no progress made, a new plan has just been made to give the support coordinator a further three months for this task. Only nine per cent of Samir's non-support coordination funds from his first plan were spent during that year. The support coordinator does not appear to understand their role or that of the guardian, or how plan-review meetings should be conducted. The support coordinator also engaged an unsuitable support service run by their own organisation without the approval of Samir's guardian. Meanwhile, Samir continues to be detained inappropriately in a high-secure mental health facility until appropriate supports are funded and implemented.
- Robert's guardian terminated the contract with his second support coordinator after concerns were raised about their conduct and quality of service by Robert, his support provider and the motel he was then staying at. That support coordinator stated they were happy to relinquish the role as they felt they were inadequately supported by their organisation to perform it.

<sup>43</sup> Ibid 120.

<sup>44</sup> "Support coordination is a capacity building support to implement all supports in a participant's plan, including informal, mainstream, community and funded supports": NDIA, Support Coordination: Factsheet for providers (2017) 2.

<sup>45</sup> "Specialist support coordination" is time-limited support coordination "within a specialist framework necessitated by specific high level risks in the participant's situation... [which] focuses on addressing barriers and reducing complexity in the support environment, while assisting the participant to connect with supports and build capacity and resilience": NDIA, Coordination of Supports: Information for providers (2015) 5.

<sup>46</sup> The Joint Standing Committee concurs with this: Joint Standing Committee on the NDIS, Parliament of Australia, Provision of Services Under the NDIS for People with Psychosocial Disabilities Related to a Mental Health Condition (2017) 77.

Given how crucial effective support coordination is to the implementation of NDIS plans – and achievement of outcomes – for people with complex and challenging support needs, consideration needs to be given to whether there are adequate accountability measures in place for support coordinators, especially because the quantum of funding approved for support coordination is sometimes extremely high. As an example, Dylan has [REDACTED] approved for specialist and regular support coordination over six months and Sue has [REDACTED] over nine months.

It is also noted that support coordination, even specialist support coordination, is a more limited role than traditional case management, as it does not fulfil functions such as coordinating the care team and ensuring appropriate communication and information-sharing between service providers.<sup>47</sup> However, despite some people with significant disability and/or complex support needs requiring this more holistic support, especially during times of crisis, the NDIS does not fund case management.

## Consequences

Even with a support coordinator, advocate or guardian to assist them, people with complex and challenging support needs are often unable to find and contract with suitable service providers or to respond assertively to poor service quality in the NDIS market. On at least one occasion, a person had to relocate in order to access services. The NDIS principles of ‘Choice and Control’ are often illusory for participants in this context.

As can be seen in stories such as Sue’s, Samir’s and Ryan’s, the difficulty of engaging and retaining suitable service providers, including competent support coordinators, hinders people being released from criminal justice<sup>48</sup> or mental health detention at the earliest opportunity. Aside from the financial cost, the harm and distress caused in these circumstances is clearly a tremendous human cost.

Delays in being able to engage a suitable service provider, as well as receiving unsuitable or poor-quality supports in the interim, often results in challenging or high-risk behaviours which in turn lead to the withdrawal of services and/or accommodation. Quite a number of stories presented in this report show that emergency and mental health services are often prevailed upon to manage a person in the absence of appropriate supports. This can result in lengthy periods of detention under the Mental Health Act 2014 (Vic) pending the arrangement of suitable supports. For example:

- Yasmin has been transported to and detained in mental health units on many occasions over the years, sometimes for lengthy periods, when support services have struggled to support her and/or withdrawn their services. Her lead support provider recently withdrew their services and she was admitted to a mental health unit again soon after, where she remains pending negotiations with proposed support providers and the NDIA.
- Dylan was admitted to a mental health unit as a compulsory inpatient after a support provider withdrew their services and he has now been detained there for six months.

Such prolonged admissions are often not clinically or legally justified, as is evident from the mental health services themselves sometimes becoming uncomfortable facilitating the person’s detention, and they significantly infringe on the person’s human rights.

<sup>47</sup> Support coordination and case management is discussed in more detail in OPA, Submission to Inquiry into Transitional Arrangements, above n 34, from 23.

<sup>48</sup> Victoria Legal Aid has also noted this consequence in respect of its clients: Submission No 79 to Joint Standing Committee on the NDIS, Parliament of Australia, Inquiry into Transitional Arrangements for the NDIS, 3 November 2017 and Submission No 91 to Joint Standing Committee on the NDIS, Parliament of Australia, Inquiry into Market Readiness, 16 March 2018. It is also occurring in other states, see, eg, Emily Baker, [‘He was returned to prison’: Detainees fall prey to NDIS process](#), The Canberra Times (online), 9 June.

Prolonged detention and the associated trauma can also contribute to further challenging behaviours and compromise the person's ability to engage with and benefit from support services once released. In some cases, this leads to people being set up in extremely restrictive, individualised (and isolative) arrangements in the community in an attempt to manage their support needs outside a formal detention environment.

When people receive unsuitable, poor quality and inconsistent support (including as a result of frequent service provider changes), it can be distressing and cause or exacerbate high-risk and challenging behaviours. People may not form therapeutic relationships with their support workers in these circumstances, which further compromises their ability to benefit from supports and achieve their goals. Poor quality and inconsistent supports can also lead to restrictive interventions being imposed on them, which has a further negative impact on their human rights and wellbeing. This was evident during the periods that Dylan, Ryan and Yasmin received unsuitable supports in the community, and when Ryan and Sue were not receiving appropriate support in prison.

The time which support coordinators spend trying to engage and retain service providers throughout the life of a plan means they generally have no (funded) capacity left to engage in any meaningful capacity building with the participant (despite this being a core function of support coordination).<sup>49</sup> Therefore, rather than being a time-limited support as the NDIA intends, the need for support coordination for people in this cohort is likely to be enduring.

A final consequence to note is that the lack of case management available under the NDIS, compounded by the withdrawal of DHHS services, the limited role of local area coordinators<sup>50</sup> and issues getting effective support coordinators and other services on board, means that guardians are sometimes asked or required to take on such functions themselves. OPA guardians are finding that a great deal of advocacy is often required on behalf of their clients who are NDIS participants; they record 60 per cent more 'actions' on these files compared to other guardianship matters. It also appears that guardianship orders are sometimes being made or renewed by VCAT to ensure that someone fulfils a coordination and oversight role when things are not going well, which is not necessarily an appropriate use of guardianship, especially when no decisions need to be made. What is often actually required is assertive advocacy.

## **Solutions and recommendations**

### ***What's already happening?***

The Victorian Ombudsman, Deborah Glass OBE, recently launched an investigation to examine whether there is a systemic issue of people with complex disabilities being held on remand for significant periods of time after having been found unfit to be tried, and whether people detained in those circumstances receive adequate supports and assistance to find suitable accommodation. Ms Glass is expected to report later this year.

A feature of the proposed Complex Needs Pathway which may assist is "individualised implementation support, with a focus on maintaining critical supports, via a plan-funded support coordinator, with responsibilities including the development of service plans and agreements, mitigating risks of service failure and coordination with mainstream support systems".<sup>51</sup> As noted above, a pilot of this proposed pathway commenced in early 2018, and a second pilot is expected later in 2018.

<sup>49</sup> The challenges for support coordinators to engage in capacity building was also identified in Libby Ellis, Kate Fulton and Luke B'osher, Summer Foundation, Support Coordination – A Changing Landscape (2017) 11-13.

<sup>50</sup> See OPA, Submission to Inquiry into Market Readiness, above n 2, 10.

<sup>51</sup> 51 NDIA, Improving the NDIS Participant and Provider Experience, above n 8, 27.

There has been a lot of discussion and recommendations regarding the issue of thin markets and providers of last resort in recent years, but limited visible progress. The Bilateral Agreement<sup>52</sup> is silent as to what will occur in the event of market failure and the Operational Plan<sup>53</sup> provides no practical framework for acting to remedy this either.

In November 2016, the NDIA acknowledged the risk of weak or thin markets (even in a mature NDIS marketplace) and stated that it was negotiating Provider of Last Resort approaches with each jurisdiction.<sup>54</sup> It also described how the agency, as market steward, can “directly commission the provision of goods and services [from providers of last resort] in order to ensure supply”.<sup>55</sup> However, it noted that states and territories lead this role and will continue to do so for providers that they fund during transition.<sup>56</sup> In submissions made to the Productivity Commission, the NDIA further stated that “it is prepared to act to reinforce thin markets where intervention is necessary to ensure market supply, and to act as a Provider of Last Resort where the market fails to provide this supply.”<sup>57</sup> In October 2017, the commission highlighted the need for more effective market stewardship by governments (including the NDIA) and recommended the NDIA release its Provider of Last Resort policy as a matter of urgency.<sup>58</sup> In February 2018, the Joint Standing Committee reiterated this recommendation, expressing “concern that Provider of Last Resort arrangements remain unclear and incomplete” and stating that “[g]reater clarity is required on how the NDIA intends to intervene in areas of thin markets”.<sup>59</sup> The Committee also recommended the NDIA develop and publicly release a strategy to address thin markets.<sup>60</sup>

In March 2018, the CEO of the NDIA stated that it is ‘putting in place arrangements to better support participants with complex needs involved in the justice system, including working with state and territory colleagues to ensure we have the right arrangements in place to Maintain Critical Supports (historically referred to as ‘Provider of Last Resort’)’.<sup>61</sup> At this time, the Australian Government also stated:

*The Government is committed to working collaboratively to address the issue of thin markets in some regions within an agreed COAG framework for building the market response to the NDIS.*

*The NDIA, as one player in this area, is actively developing a Market Intervention Strategy, to govern the circumstances in which it will intervene in markets, and an Immediate Support Response policy and framework to develop arrangements for ‘crisis’ circumstances in which participants are unable to receive supports.*

<sup>52</sup> Bilateral Agreement between the Commonwealth and Victoria: Transition to a National Disability Insurance Scheme (2015) (‘Bilateral Agreement between the Commonwealth and Victoria’).

<sup>53</sup> Operational Plan Commitment between the National Disability Insurance Agency, State Government of Victoria and Commonwealth Government for transition to the NDIS (2016).

<sup>54</sup> NDIA, NDIS Market Approach: Statement of Opportunity and Intent (2016) 15.

<sup>55</sup> Ibid 27.

<sup>56</sup> Ibid.

<sup>57</sup> NDIA, Submission No PP327 to Productivity Commission, Response to Position Paper on NDIS Costs, July 2017, 40.

<sup>58</sup> Productivity Commission, NDIS Costs, above n 36, 40, 54.

<sup>59</sup> Joint Standing Committee, Transitional Arrangements for the NDIS, above n 20, x, xiii (recommendation 18).

<sup>60</sup> Ibid, xiii (recommendation 17).

<sup>61</sup> NDIA, From the CEO – March 2018, NDIS. The NDIA has reframed the concept of a Provider of Last Resort as ‘critical support’ arrangements. OPA refers to each throughout this report.

*The NDIA's 'Maintaining Critical Supports Project' will see the development of a consistent set of policies and potential market intervention strategies to ensure key support types continue to be provided throughout the NDIS transition. The NDIA is currently consulting with state and territory governments and other key stakeholders as part of this work, and expects to release the strategy in early 2018.*<sup>62</sup>

The McKinsey & Company Independent Pricing Review, which was released in March 2018, made two recommendations in relation to thin and undersupplied markets.<sup>63</sup> The NDIA gave in-principle support to these recommendations and advised that implementation “has already or will commence by 1 July 2018.”<sup>64</sup> However, as noted above, it has since advised that progress towards implementation of the McKinsey & Company recommendations regarding complex supports will be delayed.<sup>65</sup>

In June 2018, in its response to the Joint Standing Committee, the Australian Government advised that the NDIA has committed to publishing its Maintaining Critical Supports project, including policies and processes which encompass Provider of Last Resort arrangements, following Disability Reform Council endorsement “in the first half of 2018”,<sup>66</sup> but this has not been done yet. No update was provided on when the Market Intervention Strategy or Immediate Support Response policy and framework would be released.

Finally, the Australian Government has recently announced it would invest \$64 million over four years in an NDIS Jobs and Market Fund to “to ensure the disability workforce and market can meet growing demand as the NDIS reaches full scheme”.<sup>67</sup>

### **What else is required?**

The Council of Australian Governments needs to clarify the roles and responsibilities of the Australian, state and territory governments and the NDIA with respect to market stewardship, both during the rollout period and once the NDIS is in full operation. The market steward/s should adjust market levers and policies in a coordinated way to stimulate the development of thin markets. As part of this, the NDIA should publicly release its Market Intervention Strategy, Maintaining Critical Supports and Immediate Support Response policy and framework as a matter of urgency.

NDIS pricing and funding needs to cover the real costs of service delivery to people with complex and challenging support needs and reflect the intensity of the work to be performed and skill required. It also needs to address and compensate for disincentives for services providers to take on and remain engaged with this cohort (for instance, unreliable income flows because of time spent in custody, the time it takes to engage with the person and so on). It appears that, for people with particularly complex and challenging support needs, the most sustainable model of support may be to have two different, competent service providers engaged who can alternate before burnout occurs; participants' plans should enable this to occur.

<sup>62</sup> Australian Government, Response to Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia, Provision of Services Under the NDIS for People with Psychosocial Disabilities Related to a Mental Health Condition, March 2018, 16.

<sup>63</sup> “Recommendation 11: As part of its market intervention strategy, the NDIA should adopt a clear set of metrics to more comprehensively identify and respond to risks of thin markets emerging” and “Recommendation 12: The NDIA should invest in Scheme infrastructure such as an e-market tool, which would empower participants in thin or undersupplied markets to find suitable providers”: McKinsey & Company, Independent Pricing Review, above n 31, 58-63.

<sup>64</sup> NDIA, Independent Pricing Review – Implementation Update, above n 33.

<sup>65</sup> Ibid.

<sup>66</sup> Australian Government, Response to Inquiry into Transitional Arrangements for the NDIS, above n 12, 7, 11.

<sup>67</sup> Department of Social Services (Cth), NDIS Jobs and Market Fund: 2018 Budget (2018) 1.

The NDIA will also need to support service providers, or at least service providers of last resort, to operate slightly below capacity to ensure that there is sufficient flexibility for them to provide additional services swiftly at times of crisis. This may mean enabling funding outside of individual participant plans, such as block funding, and other financial incentives. Implementing the recommendations of the McKinsey & Company Independent Pricing Review and the Productivity Commission's report on NDIS costs will also assist.

DHHS has indicated that its Intensive Support Team (IST) will, 'in liaison with the NDIA... provide high level "case management/intervention" type support for individuals as required.<sup>68</sup> However, OPA understands that such case management is only provided for short durations at times of crisis, and it is unclear whether the IST will continue once the NDIS has rolled out in full. Given its previous extensive involvement in all aspects of disability services, as well as its connections with all other Victorian government service systems, DHHS is uniquely positioned to provide case management for participants with complex and challenging support needs. This should continue to be available, where necessary, even following full NDIS rollout.

It is critical that supports and services provided to NDIS participants, including support coordination, are effective and of high quality. As noted above, the NDIS Quality and Safeguards Commission will be responsible for implementing the NDIS Quality and Safeguarding Framework in Victoria from 1 July 2019. The Commission will:

- respond to concerns, complaints and reportable incidents, including abuse and neglect of NDIS participants
- promote the NDIS principles of choice and control, and work to empower participants to exercise their rights to access good quality services as informed, protected consumers
- require NDIS providers to uphold participants' rights to be free from harm
- register and regulate NDIS providers and oversee the new NDIS Code of Conduct and Practice Standards
- provide guidance and best practice information to NDIS providers on how to comply with their registration responsibilities including how to provide culturally responsive and appropriate disability supports monitor compliance against the NDIS Code of Conduct and Practice Standards including undertaking investigations and taking enforcement action
- monitor the use of restrictive practices within the NDIS with the aim of reducing and eliminating such practices
- lead collaboration with states and territories to design and implement nationally consistent NDIS worker screening
- focus on education, capacity building and development for people with disability, NDIS providers and workers
- facilitate information sharing with the [NDIA], state and territory authorities and other Commonwealth regulatory bodies.<sup>69</sup>

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<sup>68</sup> DHHS, Tailored support for Victorian clients to access NDIS supports, above n 6, 1.

<sup>69</sup> [NDIS Quality and Safeguards Commission, About.](#)

If the Commission performs its role proactively and thoroughly, OPA hopes that it will significantly improve the quality and consistency of service provision under the NDIS. It is a concern, however, that many service provision failures will likely remain unreported and, consequently, unaddressed in this quality safeguarding system because it, primarily, relies on people with disability or their supporters making complaints. The role of the Community Visitors Program coordinated by OPA becomes all the more important in this context.<sup>70</sup> The NDIS Quality and Safeguarding Framework, and the operation of the Commission, will also need to be reviewed in the future to ensure they are fulfilling their important functions.

In addition, OPA makes the following key recommendations to better ensure that people can engage and retain suitable service providers.

### **Recommendation 8**

The NDIA should publish, consult on and implement its Maintaining Critical Supports and Immediate Support Response policy and framework as a matter of urgency. This policy and framework should ensure that:

- multiple designated providers of last resort are clearly identified
- providers of last resort are adequately resourced to enable them to respond immediately in situations of market failure which includes having staff available on short notice
- the providers and their staff have specialised experience, skill and expertise that are relevant to the specific needs of participants
- clear procedures exist to guide planners, local area coordinators and support coordinators when the need arises for a provider of last resort to provide any approved support (not just 'critical' supports)
- participant plans have built-in flexibility for situations in which a provider of last resort is required, including the ability to access contingency funding
- as soon as possible, participants are transitioned back to support outside provider of last resort arrangements
- provider of last resort mechanisms continue to exist beyond full rollout of the NDIS (and are not just a temporary or artificial market artefact during transition).

### **Recommendation 9**

The NDIA and Australian and Victorian Governments should publicly clarify who is responsible for ensuring that individual participants receive their funded supports. This responsibility must continue to be clear once the NDIS is fully rolled out.

### **Recommendation 10**

The NDIA should provide direct assistance to support coordinators who are struggling to navigate thin markets and support people with complex needs.

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<sup>70</sup> The Public Advocate, in her presentation to the Senate Community Affairs Legislation Committee Inquiry into the National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017, spoke of the key safeguarding role provided by Community Visitors in Victoria: evidence to Community Affairs Legislation Committee, Senate, Canberra, 5 September 2017, 11-12 (Colleen Pearce). OPA has also advocated for the inclusion of a community visitor function within the NDIS Quality and Safeguarding Framework: Submission to Department of Social Services (Cth), Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework: Consultation Paper, 30 April 2015, 6-12.

## Recommendation 11

The Victorian Department of Health and Human Services should:

- continue to operate its Intensive Support Team beyond full rollout of the NDIS
- provide ongoing case management for participants with complex and challenging support needs where this is required
- be prepared to act as support coordinator of last resort.

## Accessing and retaining suitable accommodation

### Themes and findings

In addition to the challenges of engaging and retaining suitable service providers, many people with complex support needs are failing to realise the transformational benefits that should be possible through their NDIS plans because of accommodation issues. Accommodation presented barriers in almost all of the stories in this report. Without suitable and stable accommodation, many of the other necessary supports cannot be implemented or will be ineffective. Accommodation for people under the NDIS was the subject of a Joint Standing Committee inquiry in 2016<sup>71</sup> and that committee recently affirmed that it remains a “critical issue”.<sup>72</sup>

Many people in this cohort are unable to live sustainably with others because of their complex behavioural presentation and low thresholds for frustration and distress (see Dylan, Yasmin, Ryan and Robert). Accordingly, shared supported accommodation and supported residential services (SRS) are often not viable options. They are also unlikely to be able to access accommodation through the private rental market due to poor rental histories, the likelihood that their behaviour will lead to property damage and/or nuisance to neighbours, and/or the cost (especially when they may need a larger property to allow space for workers providing sleepover and other supports). Therefore, most of them will need access to social housing owned by DHHS or other service providers, or SDA through the NDIS, to meet their accommodation needs.

The serious shortage of affordable housing in Victoria is well-known. Victoria has the lowest proportion of social housing units per capita of all Australian states; there are currently 82,499 Victorians on the social housing waiting list.<sup>73</sup> Even if a person is offered a property, it may not be suitable for their needs. Factors like the condition or layout of the property (such as lack of space to deescalate and for staff to retreat to) and proximity to neighbours may render it unsuitable. Furthermore, due to the propensity for some people to modify their environments and cause property damage when distressed, people in this cohort may require a property which has been robustly constructed or has other special features to render it safe for them and their workers. While the NDIA can fund home modifications, it will not always agree to do this. Accordingly, even if on a priority waiting list for housing, suitable housing may take months or years to materialise.

The following stories demonstrate the difficulty for people with complex and challenging support needs to obtain suitable accommodation in this environment:

<sup>71</sup> Joint Standing Committee on the NDIS, Parliament of Australia, Accommodation for People with Disabilities and the NDIS (2016).

<sup>72</sup> Joint Standing Committee, Transitional Arrangements for the NDIS, above n 20, 29.

<sup>73</sup> Legislative Council Legal and Social Issues Committee, Parliament of Victoria, Inquiry into the Public Housing Renewal Program (2018) 23.

- After being removed from supported accommodation where staff had assaulted and failed to support her, Yasmin was asked to leave two interim accommodation placements in quick succession, before being placed in a serviced apartment until an Office of Housing property was offered to her.
- After being removed from his supported accommodation, Dylan moved through a series of inappropriate, short-term contingency placements, including a motel and caravan parks, before being offered an Office of Housing property. It was known that the property was unsuitable for his needs. The NDIA refused to fund any modifications to it on the basis that it was public housing,<sup>74</sup> so DHHS promised to do this, however, those modifications were never made. As a predictable result, Dylan became exceedingly distressed in that environment and caused significant property damage. While on the waiting list for housing, 52 vacancies came up but were all assessed as unsuitable for his needs. There was no existing SDA that met his needs either. He has now been detained in a mental health unit for six months awaiting modifications to a new Office of Housing property.
- After spending more than one year in an inappropriate respite house, Ryan was allocated an interim accommodation property which was not robust, inadequately heated, too small to accommodate him and his workers safety and adjacent to a busy road. The poor environment, coupled with poor quality supports, meant that he never settled in the property. Despite continued advocacy over the next year from his guardian, DHHS continued to advise that there was no appropriate alternative accommodation available for him. Ryan ended up spending six months on remand before he was eventually released to a different property which had been modified for his needs.
- Robert was required to relinquish his Office of Housing property, which had suited him well, during the transition to the NDIS. The next property allocated to him was unsuitable for his needs and he ended up being evicted from it. He is unable to live in shared supported accommodation or SRS and has been unable to access private rental or crisis accommodation. Accordingly, since being made homeless, Robert has moved transiently between a number motels which are unstable, expensive and inappropriate for him. Despite continued advocacy, DHHS still has not confirmed whether Robert is on the waiting list for housing.

Because of their complex and challenging presentations, the people in this cohort are often not attractive tenants. As noted above, this had led to some people being removed from their Office of Housing properties for reasons beyond their control. While the Disability Act 2006 (Vic) contains some protections for residents of disability residential services whose behaviour may otherwise place their tenancies at risk, such safeguards are not currently replicated in the Residential Tenancies Act 1997 (Vic). The passage of the Disability Services Safeguards Bill inserts some of the existing safeguards into the Residential Tenancies Act for SDA.<sup>75</sup> Nonetheless, OPA has serious concerns about the erosion of effective tenancy safeguards for people with challenging presentations. Accordingly, the shift away from disability residential services to public and private rental properties under the NDIS means that fewer people with disabilities will have effective legal safeguards to help protect their tenancy. They also may not have the benefit of oversight from the Community Visitors Program, because while Community Visitors have the right to visit SDA rental properties, it is logistically unclear how Community Visitors will be kept up-to-date about SDA

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<sup>74</sup> This is inconsistent with the interface principles, which state that '[r]easonable and necessary NDIS supports for eligible people include: reasonable and necessary home modifications to private dwellings and on a **case by case basis in social housing** where the modifications are additional to reasonable adjustment and specific to the impact of a participant's impairment/s on their functional capacity' (emphasis added); Bilateral Agreement between the Commonwealth and Victoria, above n 52, sch 1: Arrangements for the Interface between the NDIS and Mainstream Services in Transition, attachment A: Principles to Determine the Responsibilities of the NDIS and Other Service Systems, 19.

<sup>75</sup> This report was drafted before the Bill was enacted, however this text has been updated to reflect the passage of the Bill.

tenancies. OPA is concerned that this diminution of residential rights for people with disability in the NDIS environment will lead to greater homelessness and housing instability.

Even though the Disability Act offers greater protections for people in residential services, OPA is concerned that people perceived to be too 'difficult' to manage are still being removed from their accommodation under that Act without the required steps being taken to address the underlying cause of the challenges. There is a perception that 'difficult' people may be being moved out of their supported accommodation to put the property in a more marketable position for tendering. OPA is notified of all notices of temporary relocation and eviction issued under the Disability Act and has found the rate of notices issued by disability service providers (including DHHS) has increased significantly over the last two financial years. This relocation and eviction process was invoked against Dylan, which set off his escalating accommodation crisis described above. Furthermore, OPA is aware through its Community Visitors Program that many people with disability are being relocated without the proper notices and procedures under the Disability Act being followed, which is a further concern. There is increasing uncertainty around what will happen to people being threatened with eviction compared to pre-NDIS times.

Of greater concern, is that the current level of protection provided to Disability Services clients in relation to behaviours that threaten tenancies will not be maintained on transition to the NDIS National Quality and Safeguarding Framework, and that, as a result, more people will end up homeless or in prison. OPA explored the issues regarding accommodation rights under the NDIS model in a recent submission.<sup>76</sup>

### ***Availability of specialist disability accommodation***

SDA is "accommodation for people who require specialist housing solutions, including to assist with the delivery of supports that cater for their extreme functional impairment or very high support needs".<sup>77</sup> Where the NDIA approves SDA funding, the participant can take that funding (in conjunction with their own "reasonable rent contribution")<sup>78</sup> to the SDA market and use it to pay for an SDA property. The NDIA maintains a register of all SDA properties. As part of the transition to the NDIS, DHHS registered its disability housing stock as SDA. However, while SDA funding is promising in theory, it has not yet provided a solution to many people's accommodation issues in practice. Many people in the sector are still confused about how SDA works and what the NDIA may fund. The NDIA is also tightly controlling of SDA funding, estimating that only six per cent of NDIS participants will be approved for this level of support. One example of the effects of this concerns Michael, who, despite DHHS having repeatedly advised him for many years that there are no suitable properties available in or near his region, he was never granted SDA funding during his years in mental health detention. Some guardians have also been told to wait until a specific SDA property is sourced before applying for SDA funding but, by then, the vacancy may have gone.

Furthermore, even if SDA funding is approved for an individual, it does not mean that they will be able to obtain an SDA property because there is very limited SDA stock. James, for instance, who has SDA funding approved, is living in a property which is not yet SDA registered and, accordingly, having to pay the accommodation costs himself, while Dylan was unable to find any SDA property which met his needs. The NDIA expects that the prospect of receiving SDA funds from NDIS participants will prompt investors to build and register new properties which meet SDA requirements. However, the uncertainty around SDA funding has meant that potential investors are still nervous. The practice of not approving SDA funding until a property has been sourced may also deter investors from building because this obscures the market for SDA.<sup>79</sup> OPA is concerned

<sup>76</sup> Office of the Public Advocate, Submission to Victorian Department of Premier and Cabinet, Rights in Specialist Disability Accommodation Review, July 2017 ('OPA, Submission to Rights in Specialist Disability Accommodation').

<sup>77</sup> National Disability Insurance Scheme (Specialist Disability Accommodation) Rules 2016 (Cth) r 1.2.

<sup>78</sup> *Ibid* r 5.7.

<sup>79</sup> This was noted in evidence given by the Summer Foundation to the Joint Standing Committee: Joint Standing Committee, Transitional Arrangements for the NDIS, above n 20, 31.

that, for the foreseeable future, the new SDA model cannot guarantee sufficient availability, variety or stability of housing for eligible participants (including those who should be eligible according to the legislative criteria).

Finally, it is also apparent that there is very little housing stock which can be accessed on an urgent, interim or crisis basis and which meets the needs of people with complex support needs.<sup>80</sup> As noted above, it is unclear who is responsible for ensuring that people do not become homeless in these circumstances because the NDIS transitional arrangements are largely silent on who will provide and fund crisis accommodation for people whose behaviours threaten their tenancy, and neither the Bilateral Agreement nor the Operational Plan refer specifically to crisis or temporary accommodation.<sup>81</sup> In a recent case where an indigenous man with foetal alcohol syndrome and a moderate intellectual disability was held on remand after being found unfit to be tried for 543 days due to lack of accommodation, a County Court judge raised concerns that the Victorian government was ‘vacating’ disability services and devolving its responsibilities to the NDIS.<sup>82</sup> The judge said it was the government’s role to ensure support and accommodation for this man “rather than lengthy terms of prison, which are inappropriate and unsuitable”.<sup>83</sup>

## Consequences

As a consequence of being unable to access and retain suitable housing, people with complex support needs are often forced to live in inappropriate or unstable accommodation, enter or remain in criminal justice or mental health detention and/or are thrust into homelessness. They often experience a succession of destabilising moves between inappropriate environments, which makes it extremely difficult for them to maintain their other supports and to sustain progress towards their goals. Property damage and risk of harm – or actual harm – to themselves or others are also consequences of this. The limited security of tenure in many of these forms of accommodation, especially those that fall outside the protections in the Disability Act and Residential Tenancies Act, further jeopardises the stability of any support arrangements. The stories of Ryan, Yasmin, Sue, Dylan and Robert powerfully illustrate the significant challenges and consequences of being unable to access and retain suitable housing. As explained in earlier in the report, the human and financial costs in these circumstances are tremendous.

The limited availability of appropriate accommodation also puts a strain on other service systems, such as police, emergency departments, mental health services and the criminal justice system, because people frequently present or are taken to them following accommodation and support failures. Prisons and mental health services are increasingly being treated as accommodation options for people with challenging presentations. While mainstream services have an obligation to make reasonable adjustments for people with disability, the reality is that such adjustments are limited in practice<sup>84</sup> and these services are generally not equipped to support people with complex disability support needs. In these circumstances, they may resort to harmful restrictive practices<sup>85</sup> (for instance, Sue and Ryan both suffered because of the restrictive ways they were treated in prison).

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<sup>80</sup> The President of the Prader-Willi Syndrome Association of Australia reported to the Joint Standing Committee that ‘the NDIS pricing guide for [SDA] is ambiguous in relation to respite, emergency or temporary accommodation and this is resulting in short-term facilities closing down... [or] being converted to long-term accommodation’: Joint Standing Committee, Transitional Arrangements for the NDIS, above n 20, 32.

<sup>81</sup> OPA discussed crisis accommodation in greater detail in OPA, Submission to Inquiry into Transitional Arrangements, above n 34, from 14.

<sup>82</sup> Adam Cooper, ‘Unconvicted, Indigenous, disabled man is free after 543 days in jail’, The Age (online).

<sup>83</sup> Ibid.

<sup>84</sup> ADJ, Submission to Inquiry into Market Readiness, above n 16, 25.

<sup>85</sup> Human Rights Watch has recently reported on disturbing rates of abuse and neglect of prisoners with disabilities in Australia: ‘I Needed Help, Instead I Was Punished’: Abuse and Neglect of Prisoners with Disabilities in Australia (2018).

There are also often organisational pressures to refuse admission or to discharge a person from mental health services, especially where the admission is not or no longer clinically justified, even if they have no accommodation or supports in place (see Dylan's, Con's and Robert's stories). This puts them at risk of homelessness<sup>86</sup> and imprisonment. In such circumstances, guardians are often faced with an impossible choice between advocating for their client to remain in a potentially damaging detention environment or have them released to continue the cycle of inappropriate

## Solutions and recommendations

### *What's already happening?*

The Productivity Commission's position paper noted that, under the NDIS, there is no provision available for alternative accommodation, no additional 'crisis' funding from the NDIA and it is unclear whose responsibility it is to fund emergency accommodation.<sup>87</sup> In response, the NDIA stated that it is developing a 'Market Intervention Strategy' and are prepared to ensure market supply and act as provider of last resort in cases of 'thin markets' and market failure. This is including in crisis care and accommodation situations and service gaps for participants with complex, specialised or high intensity needs, or very challenging behaviours.<sup>88</sup> However, as noted above, the degree of action towards this goal remains unclear.

In April 2018, the NDIA released its Specialist Disability Accommodation Provider and Investor Brief,<sup>89</sup> which was intended to stimulate SDA investment. However, it appears that, by introducing 'so many new contradictions, new terminology, new risks [and] new uncertainties',<sup>90</sup> it may, in fact, have a dampening effect. Concerns have also been raised that the brief "expresses a vision for SDA housing with a clear bias toward shared models of housing for people with disability"<sup>91</sup> because it states that only "a very small number of SDA eligible participants"<sup>92</sup> will receive sufficient SDA funding for a single resident dwelling. According to a joint statement released by peak disability organisations:

*Forcing participants into shared accommodation arrangements, in order for the NDIA to reduce costs, is a position out of step with the expressed preferences and goals of people with disability, let alone Australia's human rights obligations, the NDIS Act, NDIA's Independent Advisory Council advice on an ordinary life, the COAG vision for SDA and findings of international and Australian research.*

*It is also significant risk to the safety of people with disabilities as evidenced by inquiries into abuse and neglect, which have shown that people living in group homes are at high risk of violence and abuse.<sup>93</sup>*

<sup>86</sup> It was recently reported that hundreds of Victorians are released from mental health facilities into homelessness each year, and this number has been increasing: Miki Perkins, '[More go straight from psychiatric hospital into homelessness](#)', The Age (online), 21 April 2018.

<sup>87</sup> Productivity Commission, NDIS Costs, Position Paper (2017) 203. The Productivity Commission's final report reiterates this issue: Productivity Commission, NDIS Costs, above n 36, 250.

<sup>88</sup> NDIA, Submission No PP327 to Productivity Commission, Response to Position Paper on NDIS Costs, July 2017, 39.

<sup>89</sup> NDIA, Specialist Disability Accommodation Provider and Investor Brief (2018).

<sup>90</sup> Brent Woolgar, SDA: What are They Thinking? (25 April 2018) Disability Services Consulting.

<sup>91</sup> Australian Federation of Disability Organisations, Summer Foundation, People with Disability Australia and Young Care, Joint Statement on the NDIA's Specialist Disability Accommodation provider and Investor Brief (2018) ('AFDO, Summer Foundation, PDA and YoungCare, Joint Statement on the NDIA's SDA provider and Investor Brief').

<sup>92</sup> NDIA, Specialist Disability Accommodation: Provider and Investor Brief (2018) 9.

<sup>93</sup> AFDO, Summer Foundation, PDA and YoungCare, Joint Statement on the NDIA's SDA provider and Investor Brief, above n 91.

### ***What else is required?***

The NDIA should confirm that, where people have a goal of living alone, they will not be forced into shared living arrangements. OPA recognises this may not always be achievable. Equally, planners, support coordinators and others should explore housing and support models which facilitate normalisation and participation in the community, where that is desired, for people with complex and challenging support needs.

Greater efforts need to be made to provide more affordable and suitable housing stock, especially as existing stock is retired. The Australian Government recently stated that “state and territory governments, with responsibility for mainstream housing, will need to work with the Australian government, where possible, to ensure that housing supply is sufficient to ensure NDIS participants who do not receive SDA funding are appropriately housed”.<sup>94</sup> Guarantees about funding levels for extended periods of time are also required to create market confidence.

NDIA planners should proactively discuss SDA funding options with participants who may qualify. The NDIA should approve SDA requests in a timely way and include the funding in the plan as soon as it is assessed as reasonable and necessary, rather than only after a specific property has been identified.

The NDIA and market regulation will need to support accommodation providers, or at least SDA and crisis accommodation providers of last resort, to operate slightly below capacity to ensure that there are vacancies and flexibility to respond to crises as they arise. This may mean enabling funding outside of individual participant plans.

In addition to the recommendations made in its submission regarding rights in SDA,<sup>95</sup> OPA makes the following key recommendations to better ensure that people can access and retain suitable accommodation.

#### **Recommendation 12**

The NDIA, in conjunction with the Australian and Victorian Governments, should adjust market levers and policies (including the pricing framework) to stimulate and ensure the existence of sufficient numbers and diversity of crisis accommodation providers, and should also ensure that sufficient funds are provided so that Specialist Disability Accommodation provision is able to meet existing and future demand.

#### **Recommendation 13**

The NDIA should commission the provision of crisis and respite accommodation for participants who need accommodation at short notice.

#### **Recommendation 14**

The NDIA’s Maintaining Critical Supports and Immediate Support Response policy and framework should specifically address and provide guidance in relation to Specialist Disability Accommodation and crisis accommodation providers of last resort. The framework should include a vacancy management strategy for providers to prioritise clients with the most urgent need.

<sup>94</sup> Australian Government, Response to Inquiry into Transitional Arrangements for the NDIS, above n 12, 7.

<sup>95</sup> OPA, Submission to Rights in Specialist Disability Accommodation, above n 76, 4-5. Recommendations include that Community Visitors be empowered to access residents in SDA post full scheme and funded to continue their current safeguarding functions.

## Recommendation 15

The Australian and Victorian Governments should enact legislative and other safeguards to provide security of tenure and other rights protections for all forms of accommodation used by NDIS participants, including Specialist Disability Accommodation.

## Conclusion

As the stories featured in this report demonstrate, the consequences of being unable to obtain sufficient high-quality supports in a timely manner under the NDIS has a significant impact on people's human rights, dignity and statutory rights under the NDIS Act.<sup>96</sup>

Many clients are detained at the time of writing or have only very recently been released.

As occurred before the transition to the NDIS, they continue to be buffeted around between service systems and different forms of accommodation, and remain at the whim of service providers and other forces beyond their control. The lack of stability that inevitably arises in these circumstances significantly hampers their efforts to make progress towards their chosen life goals, and often puts them at risk of harm.

The stories also reveal many missed opportunities to intervene along the way to prevent crises from occurring or escalating. This situation is completely at odds with the undertakings made by the Australian and Victorian governments through the Bilateral Agreement that in the rollout of the NDIS 'participants should not be put at risk'.<sup>97</sup>

Many people with complex and challenging support needs often have large NDIS packages – though, in some cases, only as a result of strong advocacy and following periods of inadequate funding – so it is often, ultimately, not the quantum of available funding that is causing these problems. Instead, the nature of the NDIS market means that many people in this group struggle to engage and retain services, and to obtain suitable accommodation. Despite the promises, the ideas of choice and control remain illusory for many of these participants in the NDIS market. Given the significant human, financial and systems costs, the issues around NDIS market regulation and providers of last resort have lingered for too long without resolution or action.

It is notable that these stories are all current; they are not from the trial or early rollout period. OPA is concerned that these issues will remain and potentially escalate in scale and impact as full NDIS rollout is achieved unless significant and effective actions are taken immediately to ensure the NDIS delivers the intended transformational benefits for all people with disability.

## Appendix of OPA client stories

Current as at June 2018

### Samir's story

Samir arrived in Australia as a refugee when he was a teenager, without his parents.

He has long-standing diagnoses of 'treatment resistant' schizophrenia and severe anxiety. He has never had the opportunity to experience life outside a restrictive environment, having been detained almost continuously in the criminal justice or mental health system since his arrival.

<sup>96</sup> National Disability Insurance Scheme Act 2013 (Cth) s 4(1)–(3), (5)–(6), (8), (11)(a)–(b).

<sup>97</sup> Bilateral Agreement between the Commonwealth and Victoria, above n 52, sch E, cl 12.

Nevertheless, Samir is very resilient, demonstrating extraordinary patience and determination to live freely in the community.

He likes to look good and loves clothes shopping, [REDACTED] and has been known to drive a hard bargain at markets when given the opportunity. His wish is to drive a car in the countryside. He has an incredible memory for dates and names and can recall each of the consultants who have worked with him over the years. He has a deep respect for family and always greets those who are trying to help him with great respect and humour. OPA has been continuously involved with Samir, as both an advocate and guardian, since [REDACTED]

Following an incident at a Secure Extended Care Unit (SECU) where he had been detained for seven years, Samir was charged and remanded into custody. He was soon transferred from prison to a high-secure forensic hospital and was initially assessed as being unfit to be tried. A few months later, when his mental health improved, Samir was sentenced to time already served in custody. However, he continued to be detained at the same high-secure hospital on a (civil) inpatient treatment order under the Mental Health Act until he could be transferred back to the community.

[REDACTED] Samir remains detained in that hospital. Everyone involved in supporting Samir agrees that the high-secure hospital environment is inappropriate for his needs, detrimental to his wellbeing and that he needs to be transitioned to the community. The hospital has made various attempts to refer him to another SECU but these efforts have been unsuccessful, usually because the SECUs refuse to accept the referral. Samir does not understand why he is still detained in this hospital and becomes very agitated and frustrated at times, leading to restrictive measures (such as seclusion) being imposed on him and his community leave being cancelled.

The guardian consulted [REDACTED] who recommended accessing the NDIS and then proceeded to make a request for access to the scheme. The guardian found that the hospital treating team appeared to have little or no understanding of the NDIS, its processes and what was achievable for Samir under the scheme, and they had not supported him to apply to the NDIS when it rolled out in his catchment some months earlier. Two months later, the guardian contacted the NDIA to request urgent planning for Samir. He was soon after confirmed as an eligible NDIS participant.

The following month, Samir expressed his goals to the senior NDIA planner as wishing to live in the community, get a job and drive a car. The NDIA planner explained to Samir's care team that, in order to develop an NDIS plan for Samir to live in the community, evidence had to be provided to justify the request to fund a significantly high level of support. The NDIA planner asked the hospital treating team to provide the information, including risk assessments and strategies to manage that risk in the community.

Three months later, when the hospital had not provided the information, the NDIA planner suggested developing a smaller, short-term NDIS plan with a high level of funded hours for a support coordinator to work with the hospital and assist him to locate suitable housing and develop a transition plan to his new home. Samir's first NDIS plan was eventually approved six months after the access request was made, with just over [REDACTED] in supports. Of this, 41 per cent of the funds were for support coordination. The support coordinator's work was expected to be completed within three months, with a view to then seeking funding for a longer-term, community-focused plan at an NDIS review but, as explained below, the plan ended up running for the full 12 months.

Samir had received a notice to vacate his Office of Housing property, which had been vacant for several years while he was in the SECU and subsequently in custody, soon after his sentence had finished. As Samir did not want to return to that accommodation or the mental health services in that catchment, his guardian did not oppose this. However, this meant that he had no accommodation in the community to which he could be released. Accordingly, during the course of this NDIS plan, efforts were made to source accommodation in which Samir could live with

supports. However, with no SECU or Community Care Unit (CCU) willing to accept him, finding suitable accommodation has been challenging: Samir cannot access private rental because he does not have 100 points of identification and referrals to a number of SRSs were also unsuccessful. Eventually, almost six months into his NDIS plan, Samir was offered and accepted another Office of Housing property in a different catchment near his extended family, paving the way for potential release.

There have been a number of challenges in the implementation of Samir's initial NDIS plan. While the initial support coordinator was helpful, that person left and the new one has not been effective. Samir was supported to use only nine per cent of his non-support coordination funds, and most of that was spent on transport. This failure to put in place the planned funded supports has meant that Samir has been unable to progress in many of his goals.

Furthermore, during the 12-month life of the plan, the support coordinator failed to obtain the necessary evidence from the treating team in order to inform the development of a more comprehensive plan to enable Samir to return to the community (even though this was intended to be achieved within three months). This was despite regular requests and advocacy on Samir's behalf from his guardian, lawyer, mental health advocate and the Mental Health Tribunal. As the 12-month plan review approached, the support coordinator asked Samir's guardian to write a report evidencing why he required 24-hour support to live safely in the community. The guardian explained that they are a decision-maker and advocate and it is not their role to provide clinical evidence. They noted that:

*"...the purpose of the current NDIS plan has always been to enable the support coordinator to collect evidence to support [Samir]'s next plan. The evidence in the form of reports was to come primarily from the [hospital] including the risk assessment and risk management strategy and any other assessments you were to arrange relating to Samir's transition to his flat."*

They also expressed the view that those reports needed to be provided prior to the plan review in order for the review to be properly conducted. In return, the support coordinator simply stated that the review would go ahead regardless because the current plan was about to expire. As a result, the review proceeded without the necessary reports and the initial NDIS plan was extended for a further three months to enable the support coordinator more time to gather evidence and have all assessments completed to support further planning around the transition to the community – the same goal which was meant to be achieved within the first few months of the initial plan.

Despite the guardian indicating that it was unnecessary, the support coordinator actively sought to include the hospital social worker, who Samir does not get along with and who had failed to facilitate the production of the necessary evidence from the hospital during the course of the initial plan, in the plan review meeting. The guardian had to advocate strongly against this on Samir's behalf:

*"With respect, the NDIS planning process was set up to involve the participant (and their guardian if they have one), not the service providers. It is up to the participant to decide who attends the planning session. As Samir's guardian (in relation to access to services) I have made a decision about who should attend the meeting. I do not want too many people there other than those necessary – the evidence for reasonable and necessary supports needs to be provided in writing by [the hospital] including from doctors, nurses and social workers. As the support coordinator liaising with service providers including [the hospital], I believe you should attend to provide an update and any relevant points needing to be made."*

The support coordinator appeared to have misunderstood the purpose of the plan review meeting and the respective roles of the various people involved in supporting Samir, seeming to value

perceived efficiency and a 'best interests' approach to planning, over placing Samir, as the participant, at the centre of the process.

In another concerning move, the support coordinator also unilaterally engaged a service provider associated with the agency they work for to provide Samir with community access support under his NDIS plan, without first consulting his guardian (despite the guardian having the authority to make decisions regarding access to services). This was a new service, still being developed, and only employed staff during business hours, which was inadequate for Samir who would require support during planned overnight leave from the hospital. In any event, that service has since collapsed and Samir now needs a new service provider to support him to access the community. Hopefully, with some recent changes in the team supporting Samir, and with continued advocacy on his behalf, he will be able to make better progress towards his goals under this second, extended NDIS plan and soon be able to be released from his prolonged and counter-therapeutic detention.

## James' story

James is a gentle and generous young man who is very close to his family and pet dog [REDACTED]. He loves watching movies, engaging in personal training and going out with friends. Some years ago, he acquired a brain injury following a drug overdose. As a result, he uses a wheelchair and requires assistance with all activities of daily living.

James used to live with [REDACTED] who provided support to him. He would drink heavily and sometimes become aggressive. After one such episode, police were called and he was taken to hospital. In the absence of any alternative accommodation, James was moved into a retirement village, which was funded out of his DHHS ISP.

The following year, the retirement village came under investigation by Consumer Affairs after multiple complaints were raised about its financial operations and the care provided to residents. As a result of this investigation, all residents were eventually supported to move to alternative accommodation and the facility was closed.

When OPA staff visited James at the retirement village, he said that he was not engaged in any day programs or activities and was bored. He was twenty years younger than the next youngest resident. James said he did not feel that his care needs were being met in the facility and he wanted to be supported to move to alternative accommodation and be involved in activities in the community. OPA made an application for a guardianship order and was appointed as James' guardian, with decision-making authority regarding accommodation, access to services, medical treatment and health care.

The investigation into the retirement village attracted political attention. This, combined with advocacy on James' behalf, led to him being accepted as an early-entry NDIS participant prior to the official rollout of the NDIS in his catchment. Although James has SDA funding in his NDIS plan, James' guardian struggled to find suitable accommodation that was willing to accept him. As a result, James spent a short time at an SRS and was then admitted to a residential detox program. Following this, he had a long hospital admission for medical rehabilitation, necessitated by the deconditioning he experienced while in the retirement village. This had a positive impact on his physical health. Finally, James was accepted for a shared supported accommodation property. However, he cannot use his SDA funding for this because the property is not yet registered as SDA with the NDIA, so James is self-funding it, which costs around 85 per cent of his disability support pension.

A couple of months after his NDIS plan was approved, DHHS advised that it had cancelled James' ISP and would no longer provide case management or other services to him because he is now an NDIS participant. However, a support coordinator had still not been engaged to support James to implement his plan. The agency which had previously been providing services to him under his ISP

rejected the referral for support coordination on the basis that James' needs were too complex, and his guardian struggled to find another suitable support coordinator. A support coordinator was eventually engaged four months after the NDIS plan came into effect. This delay in engaging a support coordinator has had a consequent delay on James' other funded supports being implemented, and James is still not engaged in daily activities. Consequently, DHHS' decision to withdraw supports prior to the substantive commencement of alternative supports placed the progress which he had made at risk.

A further challenge to implementing appropriate supports for James has been poor communication from the NDIA. Despite multiple requests, James' guardian has still not been provided with a copy of his NDIS plan. The guardian also learned that an NDIS plan review has just taken place but they were not informed of this, and so could not participate or advocate on James' behalf. The guardian is concerned that, because James did not use many of the supports funded under his first NDIS plan (for reasons largely beyond his control), the NDIA will only approve a smaller plan this time.

## **Yasmin's story**

Yasmin is a young woman who enjoys movies, going shopping, exercising and spending time with her mother. From a young age, her presentation has been characterised by complex and poorly understood behaviours that put her and others at risk. There has been some diagnostic uncertainty; diagnoses include intellectual disability, autism spectrum disorder and schizoaffective disorder. She also has a history of significant trauma, including her experience as a refugee prior to arriving in Australia, sexual assault and the questionably-effective attempts by successive service providers to support her throughout her life.

Yasmin was put under Child Protection Services when she was a child, during an almost-two year admission to a mental health unit. On turning ██████████ OPA was appointed as her guardian. There were difficulties in the subsequent years maintaining suitable accommodation and support arrangements for her in the context of her complex behavioural presentation and strong desire to make her own decisions.

Within a few years, Yasmin was residing alone in DHHS supported accommodation, with a support provider funded through a DHHS ISP coordinated by MACNI. Yasmin exhibited some aggressive and assaultive behaviours there, often culminating in police attendance, which her support provider had difficulty managing. In response, the police would sometimes take her to hospital, where she was sometimes admitted as a compulsory patient. During one such an admission, the support provider indicated they were no longer able to support her. After a brief, unsuccessful attempt at discharge, the psychiatrist also formed the view that she could not be safely supported in the community at that time. She was transferred to a SECU. OPA considered Yasmin to be at risk of physical and sexual assault within the inpatient environment, and she was, in fact, assaulted on at least one occasion.

At this time, Yasmin's DHHS case manager and MACNI care coordinator were responsible for finding suitable accommodation to which she could be released. Yasmin's guardian believes that DHHS took little action at this time to identify or create alternative accommodation options. The MACNI care coordinator did explore shared supported accommodation, which her guardian was willing to consider notwithstanding their reservations about Yasmin's ability to live sustainability with others, however, no accommodation was willing to accept her. Yasmin's MACNI package also ended while she was detained in the SECU. The SECU staff became increasingly frustrated with the delay in finding accommodation for Yasmin and, eventually, the Mental Health Tribunal advised it would discharge Yasmin from compulsory inpatient status in the near future whether or not supports had been arranged. A short time later, DHHS advised that a private provider of supported accommodation had been identified and that a sizable ISP would be provided to fund Yasmin's placement there. Yasmin's guardian accepted this advice and agreed to the proposed accommodation. So, after more than one year in mental health detention, Yasmin was released.

Shockingly, several months later, Yasmin's guardian was advised that her new service provider was under investigation by the Office of the Disability Services Commissioner (ODSC) after a staff member made an anonymous report that Yasmin had been subject to repeated abuse, threats and unjustified restrictive practices, and that the service's inability to effectively support her and manage her behaviour placed her and others at significant risk. As a result of further information from the ODSC, as well as the service provider indicating that they could no longer support Yasmin, her guardian wrote to DHHS indicating a loss of faith in the service provider and requesting that alternative accommodation be found for her immediately. The ODSC's investigation report, which was finalised a few months later, concluded that "staff had assaulted [Yasmin] and there was a culture of violence at the house". It also found that the service provider "failed to provide suitable and authorised behavioural supports" to Yasmin and did not provide the agreed supports which it had been funded for. That service provider was subsequently deregistered and went into liquidation.

A couple of weeks after the guardian's request, Yasmin was moved into interim emergency accommodation identified and funded by DHHS. It was operated by a local community agency. This placement ended a short time later, when the agency asked DHHS to remove Yasmin from the property. DHHS arranged for this, but she was again asked to leave after a short period because of repeated property damage. DHHS then arranged for her to move into a serviced apartment, where she remained for a couple of months until she was offered and accepted an Office of Housing property.

During the ODSC investigation, Yasmin's guardian asked DHHS to identify a support provider with the expertise to understand and engage with Yasmin's complex presentation, and to develop a model for working with her successfully. A support provider was engaged on an interim basis while longer-term options were explored. However, this support provider experienced challenges in supporting Yasmin, and a number of incidents led to police attendance and transport to hospital. There, mental health staff would generally determine that Yasmin's behavioural presentation was driven by her complex personality and associated impulses, rather than the result of psychosis. Yasmin's guardian also agreed with this view. However, the support workers' continued assertions that Yasmin was displaying psychotic symptoms appeared to compromise their willingness and ability to consistently implement the recommended behaviour management strategies. The support workers started to inform other services, such as police and mental health, that they could not support her.

A new service provider was identified as the best candidate to take over Yasmin's long-term support. They were initially reluctant to accept the referral and funding package. After DHHS applied some pressure, they agreed to provide a part-time, in-home clinical support service but stood firm in their refusal to provide the 24-hour model requested of them. Yasmin's guardian accepted DHHS' proposal to keep the interim support provider on to provide the additional hours of Yasmin's support model, including sleepover support, but that provider eventually withdrew in response to the numerous incidents. DHHS then arranged for another support provider to cover those additional hours.

Around this time, at DHHS' suggestion, Yasmin's guardian made an access request to the NDIS, two and a half months after the NDIS rolled out to Yasmin's catchment. Yasmin did not receive an approved NDIS plan until seven months later. While the value of the plan was significant, it was [REDACTED] lower than the combined quotes from Yasmin's support providers. It was insufficient to fund her current 24-hour support model and also meant that there was no provision for additional staff at times when Yasmin needed extra support. Her DHHS case manager was initially concerned that, even though Yasmin was doing well, her situation would decline if her ongoing supports were not appropriately funded. However, they felt that the NDIA was responding to these concerns appropriately. As time passed though, it became increasingly clear that the NDIA was not responding.

Yasmin's lead support provider initially indicated that they would also provide support coordination under her NDIS plan. However, some months later, that provider decided that it would not provide support coordination services. There were some difficulties locating another suitable support coordinator for Yasmin because not many services had experience working with clients with such complexity and, because the NDIS rollout was still in its infancy, many services potentially willing to assist had not yet recruited a workforce.

The decision was also somewhat pressured due to DHHS' indication that it would soon cease providing case management. DHHS recommended a new support coordinator, who Yasmin's guardian accepted. It took many months before a service agreement was signed between OPA and the new support coordinator, in part because of differing understandings about the scope of OPA's authority, as guardian, to enter such contracts on Yasmin's behalf but also because of the support coordinator's limited engagement. Yasmin's guardian perceived that the support coordinator was avoiding the matter and stringing them along when they made enquiries. The support coordinator was also very slow to respond to the care team's desire for a review of Yasmin's NDIS plan, to increase funding for the supports she required. Eventually, the DHHS case manager lost patience and complained to the support coordinator's employer, which resulted in a new support coordinator being allocated who displayed much greater focus and competence. Nevertheless, because of these delays, Yasmin's plan was not reviewed until ten months into the existing plan.

During the course of the plan, the following significant deficits in Yasmin's NDIS support package became apparent to Yasmin's guardian:

- The team of allied health professionals, who had been funded through Yasmin's ISP to provide clinical leadership around her support, were not funded under her NDIS plan.
- There was no provision for regular meetings between Yasmin's support providers. This had been a feature of her support arrangements prior to the transfer to the NDIS. The service providers reported that this closed off opportunities for communication, behaviour management planning and monitoring the sustainability of the support arrangements.
- There was no provision for staff from the secondary support provider to receive training or support in relation to behaviour management from the lead support provider (who was responsible for developing behaviour management strategies for both service providers). As a result, they largely did not follow the recommended strategies.
- The lead support provider advised that the existing support arrangements involved an unacceptable organisational risk and indicated that they intended to cease supporting Yasmin.

The cycle of support workers calling police and taking Yasmin to hospital for short admissions in response to challenging behaviours continued throughout this time, with the hospital indicating a reluctance to continue accepting Yasmin in these circumstances. Around seven months into the NDIS plan, Yasmin's lead support provider confirmed an intention to withdraw services, citing concerns about staff safety and Yasmin not fitting within the service's preferred support model. Yasmin also received a notice that she was in breach of her tenancy obligations following damage caused to a neighbour's property, and she was charged with a number of offences by police, including in relation to some serious unprovoked assaults on members of the public while in the company of support workers.

It was very difficult to identify another provider willing to support Yasmin, so her secondary support provider was asked to step up to provide full-time support as an interim measure. Another support service with experience supporting complex clients with mental health difficulties was eventually identified who indicated a willingness to take over Yasmin's daily support, support coordination and behaviour management support. Because they would not be able to start providing services for at

least four months, which was after the expiry of the NDIS plan, it was planned that the NDIA would provide a short-term, interim plan to continue existing services while the proposed service provider put together a service proposal.

Following the plan review, the NDIA approved an interim plan with over [REDACTED] of supports over four months. Pro rata, this was almost double the rate of funding under the first plan and included additional hours for support coordination. Nevertheless, the plan does not contain any funding for specialist behavioural support and Yasmin's guardian continues to have concerns about the lack of supported community access and opportunities for social interaction being provided to Yasmin under the plan. The guardian has also been frustrated by the NDIA's lack of transparency, which makes it difficult to advocate to the actual NDIA decision-maker, and by the NDIA's limited communication, including failing to provide relevant information, which makes it more difficult for the guardian to fulfil the role of making access to service decisions in Yasmin's best interests.

Prior to the commencement of the interim NDIS plan, the proposed service provider had provided a quote for proposed services to the NDIA. After some months of uncertainty, the NDIA advised it considered this quote to be too expensive. The NDIA planner identified a second proposed service provider and gave them information to enable them to also provide a quote for taking over Yasmin's support. This process will not be finalised before the expiry of the interim plan, so a further interim plan will have to be made. The existing support provider, which had stepped up to providing full-time support to Yasmin as an interim measure some months ago, may not be willing to continue providing services under a further interim plan because they are owed almost [REDACTED] from the NDIA for services already provided.

Meanwhile, Yasmin's mental health and behaviours have continued to deteriorate and she has again been admitted to a mental health unit, where she is detained as a compulsory inpatient. At this stage, the future of Yasmin's supports remains uncertain and, in the absence of an experienced and effective support provider who can provide consistent, stable support to her into the future, it will remain difficult for Yasmin to make significant progress towards her life goals.

## Oliver's story

Since he was a young child, Oliver's life has been impacted by loneliness, isolation and hostility, leading to a lifetime of substance abuse, violence and serious mental illness. Following the completion of a sentence of imprisonment, he has been detained in a high-secure mental health facility as a compulsory inpatient for [REDACTED]. Referrals to transfer him to less restrictive facilities over the years have not been accepted. Oliver struggles in knowing how to live in this world and at times does not want to leave the hospital. However, every now and then, he is able to reflect on and apologise for his behaviour. This ability to demonstrate some insight is reason to be optimistic that, with the right support, he may be able to build on this simple but important strength.

The NDIS rolled out in Oliver's catchment two years ago. Having tailored supports funded under an NDIS plan could enable Oliver to transition to a less restrictive facility. However, as Oliver does not accept the diagnoses which have been given to him, he did not want to engage with the NDIS or any other services. Accordingly, he was not referred to the NDIS until a year later. After he was accepted as a participant, OPA was appointed as his guardian to make decisions regarding access to services.

The meeting for Oliver's first NDIS plan was initially delayed because he was being held in seclusion. However, it then took months of advocacy to the NDIA by Oliver's guardian for another planning meeting to be arranged, which did not take place until six months after he had been accepted as a participant. The meeting, which took place at the facility, focussed on what services Oliver would need to be supported in the community and was described by Oliver's guardian as very productive. Oliver's social worker had prepared a detailed table, setting out his support needs and the NDIA planner who attended was switched on and appeared to understand what Oliver's care team were advocating for. However, when the approved plan arrived, it was disappointingly

small – around ██████ over 12 months, with two thirds for an occupational therapy assessment and individual skills training and the rest predominantly for support coordination. It was clearly inadequate to implement the high levels of supports that had been discussed and would be needed to enable Oliver to be released from detention. Oliver’s guardian considered appealing the NDIS plan but decided instead to use the approved support coordination funds to develop a more comprehensive plan for the required supports, and then advocate strongly for an early plan review.

A suitable support coordinator was identified at the planning meeting and a referral made to them shortly thereafter. There were some delays in that support coordinator coming on board while they waited for information from the social worker at the facility. Some months later though, before any support coordination had commenced, the social worker advised that there is a possibility that Oliver may be able to be transferred to a secure mental health facility ██████ which is planning to open some new beds. Accordingly, a decision was made to change support coordinators to one which also provides services ██████ to enable continuity in the event that Oliver is able to be transferred there. At this stage, nearly nine months after Oliver was accepted as an NDIS participant and more than a quarter of the way through his current, minimal NDIS plan, no significant supports have been able to be implemented and Oliver still appears to be a long way away from being released from the high-secure facility.

## Brian’s story

Brian was released from a specialist disability detention facility some years ago after completing a ██████

Since his release, he has been subject to close supervision and compulsory disability treatment to reduce the risk of him harming others. Prior to the NDIS, all of Brian’s supports and services were funded by DHHS, including through an ISP. However, when Brian became an NDIS participant, the NDIS plan had a shortfall of over ██████ worth of clinical services funded compared to what had been funded by his ISP. As a result, he went from having fortnightly one-on-one individual psychology sessions at his home to only 15 sessions a year at a less convenient location (also meaning that more of his outreach support hours were used up transporting him to and from his clinical sessions). There was also no funding for his psychologist to attend care team meetings or for updated risk assessments to be conducted. The psychology sessions supported Brian to develop and maintain skills in relation to emotional regulation, social interaction and communication. The treating team advised that the drop in individual psychology sessions has had a detrimental effect on Brian’s presentation and significantly compromised his ability to achieve his goals. Similarly, his psychologist expressed concern that the changes have [had a] considerable impact on the clinical governance and holistic approach in the care, management and supervision of [Brian], and subsequently, on risk manageability. As a result of these concerns, DHHS agreed to continue funding the psychology sessions.

After raising these concerns with the DHHS IST, Brian’s support coordinator requested a review of the NDIS plan, citing the above concerns and providing new reports in support of the request to obtain funding to continue the necessary supports. The NDIA confirmed receipt of the plan review request on a number of occasions but never organised a plan review. In the meantime, the support coordinator exhausted all their funded hours under the existing plan. In the end, no plan review took place until the expiry of the plan, over eight months after a plan review had been requested. If adequate funding for the supports necessary to address his complex treatment needs is not provided, there is a real risk that Brian will not be able to meet his treatment goals or maintain his risk at an acceptable level, which places him at risk of future detention.

## Sue's story

Sue has a complex but unspecified pervasive developmental disorder; her presentation has been described as unique and severe. Although a recent intellectual functioning test assessed her [REDACTED] testing as a child showed a higher IQ, with significant variation between her verbal and performance scores and, accordingly, she does not fall within the definition of intellectual disability. Similarly, while she has significant autistic traits, she does not meet the diagnostic threshold for autism. In addition, while she has at times been diagnosed with schizophrenia, most recent assessments concur there is insufficient evidence for such a diagnosis. Because of this diagnostic uncertainty, there has been a longstanding deadlock dating back at [REDACTED] between mental health and disability services as to which system is responsible for meeting her needs.

Sue was remanded into custody in relation to [REDACTED]. She was assessed as being unfit to be tried in relation to the charges. Despite the anticipated delay in finalising the matter, she was considered unsuitable to be bailed because there was no suitable accommodation or support services in place to assist her in the community. While in prison, Sue vocalised her extremely high levels of distress by screaming loudly, which caused her to be the target of verbal abuse from other prisoners.

Although Sue was ineligible for disability or mental health services, she was referred to the NDIS five months after she was remanded and was accepted as a participant. OPA was appointed to act as Sue's guardian soon after, with decision-making authority in relation to access to services, accommodation, access to persons and health care. Even though she had been accepted as an NDIS participant, there were significant limits on what supports could be funded under an NDIS plan while she was in prison. Her initial NDIS plan, made six months after she became a participant and which was to last for 12 months, only provided around [REDACTED]. Support coordination was a vital component of this plan, given the complexity of Sue's situation and the need to work across multiple service systems in order to develop a release plan. However, Sue's guardian struggled to engage a support coordinator to assist her because all suitably experienced support coordinators either declined the referral due to the complexity or did not have capacity to take it on. Furthermore, Sue's future needs could not be adequately assessed while she was in prison and it was deemed too difficult to identify what supports she would require, once released.

At this stage, Sue's guardian found the NDIA difficult to engage with. Its officers refused to attend case conferences or to engage in the assessment and service planning which would be necessary to enable her to be released from prison. As a result, no additional supports could be added to her NDIS plan and she remained indefinitely detained in prison without any disability supports. Sue's guardian advocated directly to the NDIA, requesting assistance to help break the impasse and to recommend a suitable support coordinator, but she found that Sue's NDIA planner was unhelpful and did not respond to many of her phone calls or emails.

By this time, the judge presiding over Sue's case indicated that he was deeply concerned about her situation. The judge indicated that, if the disability and mental health service systems did not step up, he would ensure public attention and scrutiny by asking the departmental secretaries to publicly explain why support had not been provided.

A support coordinator was eventually engaged, who prepared a thorough proposal for a 12-month NDIS plan which included the supports Sue would require after being released from custody: two on one in-home support 24 hours a day plus other supports including specialist behavioural interventions, assessments and specialist support coordination. The proposal, which was supported by the Senior Practitioner for Disability and other independent experts, was priced at [REDACTED]. Sue's new NDIA planner was far more helpful and had a much better understanding of Sue's complex situation and needs. Nevertheless, during this time, Sue was still not receiving the supports she needed in prison and, consequently her emotional wellbeing and behaviour continued to deteriorate. As a result, she was being held in isolation for 23 hours a day due to her extreme

levels of distress and inability to maintain non-disruptive behaviour in the presence of other prisoners.

After two month's consideration, the NDIA approved Sue's revised NDIS plan. Despite the magnitude of funding approved (██████████ over nine months), additional supports were also required outside her NDIS package to enable her transition to the community. For instance, MACNI funded modifications of a surplus three-bedroom standalone house, mainstream services provided counselling to Sue, and the prison allowed the support workers who would be working with Sue in the community to spend time with her in prison in preparation for her release.

Three months later, after 17 months on remand, Sue was finally released from prison. The trauma she experienced in that environment has undoubtedly been detrimental to her recovery, and led to a much more intensive NDIS plan of supports being required in order to support her safe reintegration into the community.

Within a few months of release, Sue was doing relatively well in her new home. Her support workers focussed on building rapport and working to understand the best way to respond to her when she was distressed and to avoid triggering her. With their support, Sue started to become increasingly independent. For instance, she enjoyed going to the grocery store or to the café on her own and began taking the lead in some household tasks like laundry. Improvements were slow but, nonetheless, noticeable, which was to be expected with any person with such complex needs who had experienced significant recent trauma. Sue's service providers were also thorough in their risk management planning, and collaborated with relevant non-NDIS supports such as the local police, Police Ambulance and Clinical Early Response, the Crisis Assessment and Treatment team and the nearest emergency department.

Even with these improvements, the transition was challenging. Sue sometimes left the property without staff knowing where she was going. She would be found by the police and returned home but, sometimes, not until days later. Sue also returned to her parents' property on a number of occasions, in breach of the intervention order, which put her at risk of further charges and potentially being remanded. She also had periods when her emotional state was so heightened that she required medication to help settle. While she does not have a mental health diagnosis, Sue does experience delusions. As she cannot be medicated by her support workers, this requires ambulance attendance and admittance to the emergency department for monitoring, which Sue finds very distressing. The guardian was concerned that Sue's physical and psychological needs were still not well-understood, and sought and obtained agreement from the Victorian Dual Disability Service to undertake a review of her situation.

When heightened, Sue continued to vocalise her distress by screaming which could be heard by neighbours. At one point, some temporary respite accommodation was arranged.

DHHS also advised that the house was scheduled to be sold this year. DHHS explored housing options for Sue and advised there was only one property available. Sue's guardian decided not to pursue this option because her support provider and staff would not be able to support her in that location, but continued to explore other future options.

Given Sue's tenuous living situation, her guardian decided to move her to the only accommodation available at short notice – a caravan park. While it was acknowledged that this move would be difficult for Sue, her guardian considered that the consequences and risks associated with her remaining in the property would be far greater.

Sue's support workers continued to provide support to her in the caravan park. However, after a few days there, her distress and behaviours escalated and became unmanageable. After brief stays in two motels, Sue's guardian then agreed to her being admitted to a general hospital ward via the emergency department on a less-than-ideal temporary basis until more reliable short-term accommodation could be found. Her support workers continued to provide 24-hour support in the hospital but, over time, Sue's distress and behaviours escalated and she was regularly physically and chemically restrained in the hospital.

Sue's support coordinator took a staff member offline to look for rental accommodation full-time. The property had to be in a low-density area which could be serviced by her current support provider and neither too close nor too far from her family. An application was also submitted to the NDIA for SDA funding.

Finally, after a few weeks in hospital, Sue's support coordinator was able to source a private rental property for 12 months. The rent will be collectively funded by Sue, her support provider and MACNI. MACNI has also agreed to pay for any furnishings, damage and respite required. Sue has just been released from hospital to this house. In addition, the NDIA has just approved Sue's application for SDA. Her support coordinator sourced alternative accommodation which will be designed to meet Sue's needs.

While her situation remains fraught, it is hoped that, once her new home is provided, it will bring an end what has already been more than two years of harmful disruption and crisis in her life.

## David's story

David is non-verbal, has a significant intellectual disability and severe autism and many entrenched anti-social behaviours against women. However, due to the profound nature of his disability, he does not understand his behaviours are potentially criminal in nature. Police have been called in response to his behaviour but, to date, no charges have been laid against him. After recently moving to Victoria, OPA was appointed as guardian with decision-making authority in relation to accommodation and access to services.

David's parents are divorced and live about [REDACTED]. He has spent time living with each of them over the years, with supports provided under an ISP. Concerns have been raised in relation to the ability of both parents to appropriately support David, as they have not always allowed support workers to implement appropriate strategies nor respected the authority of David's previous interstate guardian. Within the last year, both parents have unilaterally relocated David to their home without the permission of his guardian.

Just after David was relocated back to regional Victoria, his first NDIS plan was approved. The plan provides for around [REDACTED] of supports over six months, including specialist behaviour support intervention and specialist support coordination. Within a week of the plan commencing, DHHS advised that it would no longer be providing any services or case management for David.

Despite the funding available, it proved extremely difficult to engage suitable support providers to support David in regional Victoria. The agency which had been providing support previously would not agree to provide services under the NDIS plan because it did not accept the service agreement contract which David's guardian sought to use, and there was no other local provider with capacity or willingness to work with David. Because appropriate services could not be purchased for him in the thin disability services market in regional Victoria, David's guardian made the decision to relocate him to Melbourne to live with his other parents. By being based in [REDACTED], David will have greater access to day programs, a greater pool of appropriately trained and consistent support workers, specialist therapists and doctors, and a greater stock of supported accommodation potentially available to him. Shortly after moving back to [REDACTED], service agreements were signed with a support provider and a specialist support coordinator.

Despite the stated primary goal of David's NDIS plan being to organise short-term and, eventually, long-term supported accommodation, there is no express provision in the plan for scoping or securing accommodation. There is, however, funding for short term accommodation and assistance required at the high intensity rate. Due to his challenging, ritualised behaviours, David is unable to live safely with others, which means that a lot of supported accommodation options are unsuitable for him. Accordingly, he needs his own two-bedroom property to be able to receive the

24-hour support he requires. However, he is unable to afford such a property himself and the NDIS has not provided any SDA funding. As his parents are unable to continue accommodating him despite his existing supports, David's support coordinator is continuing to seek shared supported accommodation, however, it is unknown when a suitable place will be found.

## Dylan's story

Dylan is a polite young man with a great sense of humour and a range of endearing qualities and strengths. A naturally reserved person, he has a strong desire to be liked or accepted. He loves his footy and enjoys the opportunity for one-on-one interactions around his interests, including building and construction. He has long-standing diagnoses of severe autism spectrum disorder, generalised anxiety disorder and Tourette's syndrome.

Dylan became an NDIS participant during the Victorian pilot [REDACTED]. Around this time, a purpose-built group home was established in the region to accommodate seven people with disabilities who had each experienced challenges sourcing appropriate accommodation. Dylan was accepted into the home. His first few years there were relatively settled, with a consistent day program and consistent, dedicated staff. However, when instabilities in staffing and other disruptions arose in both his day and home supports, Dylan developed a range of escalating behaviours which put his safety and that of staff and other residents at risk.

Dylan's behaviours led to increases to his medication, increased restrictions (including chemical restraint and reduced community access), frequent engagement of emergency services and a belief by support workers that he could no longer remain in his home. Dylan's psychiatrist considered that his escalation in behaviours were his response to his environment. A recent assessment noted that the complete collapse of formal structures around Dylan [at this time] led to what can arguably be described as a complete collapse in Dylan's capacity in all areas. It is significant that Dylan had previously lived in supported accommodation for more than [REDACTED] without demonstrating this level of challenging behaviour. His behavioural consultant also expressed concern about the quality of the supports being provided to him, including their overly restrictive and punitive nature. The behavioural consultant wrote in an email to Dylan's OPA guardian and the Senior Practitioner for Disability that they held "grave concerns for [his] wellbeing if he continues to reside in such an environment".

Following a review, Dylan's NDIS plan was increased to fund 2:1 support during waking hours. However, the support provider could not implement this due to risk of injury to staff. The support provider then commenced the eviction process under the Disability Act by issuing Dylan with a notice of temporary relocation and subsequently a notice to vacate (which was later found by VCAT to be invalid). An application for a further NDIS plan review was also made. OPA was appointed as Dylan's guardian a short time later, with authority to make decisions regarding accommodation and access to services (later expanded to include decisions regarding medical treatment).

DHHS, in its role as Dylan's NDIS support coordinator funded and, in consultation with the support provider, decided that Dylan could no longer live in the group home and removed him without his guardian's consent. Concerned that this decision would render Dylan homeless, his guardian responded, "By exiting him Thursday you've nominated yourself as the person responsible... If you are asking me to cease lease/tenancy at [the group home] then DHHS need to put in writing that they will take responsibility for housing him." What followed was a series of inappropriate, short-term contingency placements, including a motel and two caravan parks. After some delays with the NDIS plan review, a new three-month NDIS plan was approved to provide a model of transitional support while suitable accommodation and support providers were being sourced. This new plan was formalised shortly after Dylan had accepted and moved into an Office of Housing property.

This series of accommodation changes was exceedingly destabilising and stressful for Dylan, given his need for consistent and predictable environments and routines. The fabric and design of the motel, caravan parks and Office of Housing property were also inappropriate for his sensory needs and behaviours. They triggered his anxiety which prompted him to modify the environments in a way which caused significant damage. Furthermore, he was not engaged in any formal day support programs throughout this time. While service providers continued to debate appropriate models of support and the associated funding for them, Dylan's situation and behaviour continued to deteriorate. Despite promises that the Office of Housing property would be modified to cater for Dylan's needs, such modifications were never made and so the property remained unsuitable for him. The NDIA refused to provide funding for this, advising Dylan's guardian that the NDIS does not fund modifications to public housing. While Dylan worked hard to manage his anxiety as long as he could, it eventually proved overwhelming and he consequently damaged the property to the extent that the support provider refused to continue providing services due to occupational health and safety issues. A new support provider was engaged but it was under-prepared to support Dylan effectively, which caused him further distress. He ended up leaving the Office of Housing property without staff support and did not want to return. As a result of her concerns about Dylan's increasingly heightened presentation and lack of appropriate supports, his guardian then made the decision that Dylan should present to a mental health unit for review of his anxiety, current circumstances and medication. Following assessment, he was detained as a compulsory inpatient under the Mental Health Act.

Some months earlier, Dylan's application for priority access to supported accommodation was accepted by DHHS and he was placed on the Victorian Housing Register. However, each of the 52 housing vacancies that have arisen since then have been assessed by his care team as unsuitable for his needs, so his guardian decided not to apply for any of them because of the risk that inappropriate accommodation would pose to Dylan and others. Furthermore, no SDA properties that met Dylan's requirements could be located for him. In the absence of any suitable accommodation, the only options were for a new SDA property to be built or for substantial modifications to be made to an existing property.

After he had been in hospital for a month or so, DHHS made another Office of Housing property available to Dylan. The property requires substantial remodelling and construction to ensure it is sufficiently robust and appropriate for Dylan's support needs. The following month, Dylan had a further NDIS plan review. The new plan lasts for six rather than 12 months to ensure identified assessments are completed, and evidence sourced to ensure future planning goals and funded supports are appropriate to [Dylan]'s daily needs, models of housing and to reduce risk to Dylan and his support network. It includes [REDACTED] for 'home modifications' pending the outcome of assessments and evidence provided by his care team. It is understood that this funding is for the building project manager to consult, develop plans and project manage the modifications, rather than for the actual building work. Dylan's guardian was advised that the NDIA agreed to pay a significant quantum for these modifications, however, no such funding appears in the plan and it has been very difficult to get clear communication from the NDIA regarding it.

After thorough consultation with Dylan's care team, the building project manager developed plans for the required modifications. However, despite the NDIA's apparent agreement to fund the modifications, no building work has yet commenced. In order to make progress, DHHS offered to pay for the modifications upfront and receive reimbursement from the NDIA later. However, the NDIA did not agree to this approach, stating that the proposed process did not meet its requirements about how building work should be tendered. Three months into the plan, there was still no concrete advice on when the work would start.

By this time, Dylan had been detained for six months in the mental health unit. He is understandably fixated on when and to where he will be released, and the delays and uncertainty are very challenging for him. His health and behaviour are deteriorating in this environment, and he is mostly accommodated in the low-stimulus area of the unit to minimise distressing triggers. His support provider expressed reluctance to facilitate community access because of how long he has been isolated in the mental health unit, which means that risks which were previously manageable

in the community may no longer be so. Transport is also an issue, as a safety screen which needs to be placed in a vehicle to enable staff to transport Dylan safely has not been funded. In addition, the NDIA initially expressed reluctance to fund his support provider to provide core supports (funded [REDACTED] his current plan) to him while he is detained in the mental health unit, on the basis that the unit should be meeting these needs. The mental health unit staff are not equipped to properly support someone with his disabilities, and ongoing engagement with his support workers as well as access to the community with them are essential if he is to be able to successfully transition to the community in the future.

As the delays dragged on, the service became increasingly concerned that Dylan's distress and challenging behaviours could not be adequately addressed in an acute mental health inpatient unit. Furthermore, the way in which Dylan is being supported necessitates other patients being treated in a more restrictive manner than necessary. In good faith, Dylan's care team had been regularly reassuring him all year with the consistent message that a property had been obtained for him, would be modified to meet his needs and he would move directly from the mental health unit into his new home. If he does have to leave prior to the completion of modifications to his new home, Dylan will be very distressed that the message he was given all year was untrue, which may compromise his relationship with his care team.

Some interim accommodation options have been proposed in the event that Dylan has to leave the mental health unit before his property is ready. At the guardian's request, clinicians from Dylan's care team assessed the suitability of each proposed property. They reported that the properties were in overall disrepair, lacked space for Dylan to be able to disengage and defuse, lacked adequate staff 'escape' routes and presented numerous other significant concerns. No funds would be available to modify an interim property. As with the motel, caravan parks and previous unmodified Office of Housing property, the distress that would be caused to Dylan by being forced into an inappropriate environment would predictably lead to further property destruction, withdrawal of service providers and a cycle of homelessness and/or detention in the criminal justice system. In fact, Dylan's support provider and the service providing specialist behavioural interventions have already advised his guardian that they would not provide services if Dylan were placed in inappropriate accommodation that put him and staff at risk. In these circumstances, Dylan's guardian decided she was unable to consent to any of the interim accommodation proposals because it was not possible to conclude that the environments would be safe for Dylan, service providers or the public. Although OPA acknowledges the current infringement on Dylan's human rights, and indeed those of the other patients, it is OPA's view that remaining in the mental health unit until the modifications to his property are completed remains the lesser of two unpalatable options.

The NDIA has just confirmed that builders have now been selected and that the modifications to Dylan's property will commence soon and be completed in a month. It is hoped that this runs to plan. Even if it does, despite having been an NDIS participant for five years and having a significant NDIS package, and despite the ongoing, concerted efforts of his large and very active care team, Dylan remains in extremely tenuous circumstances.

## **Michael's story**

Michael loves all things to do with cars and motorsports, and is an Aussie car fanatic. He enjoys going out and eating food with his friends, spending time with his family and meeting new people (particularly to talk about cars). He has been diagnosed with an intellectual disability, schizophrenia and another medical condition which requires close supervision of his behaviour in order to protect his physical and mental health. He has been detained in a SECU as a compulsory inpatient under the Mental Health Act for almost a decade.

It has been noted for many years that he is compliant with his prescribed treatment and that his mental health is stable. He is frustrated and, at times, struggles to cope with being detained for so long. His goal is to live by himself or with other males in the community with supports, and to get a

'proper' job doing something with cars. His treating team agree he would be better off in a less secure environment. They also agree that he would require 24-hour support, and, ideally, some home modifications, to manage the health risks associated with his medical condition.

Michael's treating team, as well as various advocates and the then Mental Health Review Board, have attempted to source suitable accommodation and facilitate a pathway out of SECU for Michael over many years. Because of his dual disability, questions have, at times, been raised about whether Michael would be better supported in a residential environment designed for people with disability or mental illness, and which service system bears responsibility for meeting his needs. A trial some years ago at a CCU broke down very quickly because the supports provided there were inadequate for his needs.

Concerned about his lengthy detention in an environment that is not best-suited to his needs, OPA commenced advocating assertively on Michael's behalf some years ago, including writing regularly to the relevant regional director of DHHS and to the then Mental Health Review Board. In OPA's opinion, Michael's needs would be best addressed through disability accommodation and supports, rather than through the mental health system. OPA also expressed concern about a proposal to discharge Michael back to an SRS where he had previously resided with inadequate supports, which had led to him becoming distressed, destroying property and harming the proprietor.

For at least five years, DHHS had agreed that Michael requires age appropriate stable accommodation within a specialised disability-specific group home environment or specialised housing model which will offer him the normalities of life appropriate for a person of his age and level of disability, and noted his requirements for his own bedroom and separate living area to ensure he has a safe quiet space to go at times of stress, when psychiatrically unwell, and to ensure he has privacy. DHHS completed an application to the Disability Support Register (which is the process for him to be considered for accommodation vacancies within both the government and community sector) but, through all this time, no suitable vacancy has come up in or near his region. Michael has reportedly had no government support or contact in the last 18 months.

The NDIS rolled out in Michael's catchment over a year ago. He had a [REDACTED] NDIS plan approved soon after, which included [REDACTED] for support coordination to assist [among other things] with sourcing appropriate accommodation options and liaising with the Vacancy Management Unit at DHHS. Given the barrier to Michael being discharged over many years has been lack of suitable accommodation, it is unclear why he was not supported to apply for, or was refused, SDA funding or other supports to help to modify a property and maintain a tenancy as part of this plan. Unsurprisingly, once again, no vacancies were offered to Michael during the course of this plan so he remains detained in the SECU.

OPA was recently appointed as Michael's guardian with decision-making authority in relation to accommodation and access to services. Michael's NDIS plan has also just been reviewed. His support coordinator attended the planning meeting with a detailed proposal for accommodation in a small shared facility it operates, which is staffed 24 hours a day and provides high-level mental health support. The cost is around [REDACTED] a resident a year. Thankfully, the NDIS agreed to fund this as part of a new [REDACTED] plan. After almost a decade of detention, Michael finally has a pathway to transition out of the SECU and is now looking forward to building a new independent life in his community.

## **Ryan's story**

Ryan is a young man with autism and intellectual disability. He has a number of strengths and is proud to have finished high school. However, he also has a history of assaulting [REDACTED], as well as property damage due to his disability. His challenging behaviours resulted in him being unable to live with his family and so, a few years ago, he was placed in a DHHS respite house.

Ryan was isolated in the house, largely confined to his room with no activities, and the casual support workers were not suitably trained or experienced to support him appropriately. Ryan engaged in property damage and assaultive behaviours toward his support workers, and he and the workers were unsafe in this environment.

While in respite, OPA was appointed as Ryan's guardian to make decisions regarding accommodation, and advocated for more stable and appropriate accommodation and support for Ryan. This advocacy resulted in a DHHS case manager being allocated. When this case manager left DHHS a short time later, Ryan's case management was sub-contracted by DHHS to an external service provider, but he had to wait a few more months before a case manager was allocated.

Not long after, Ryan was charged with assaulting members of the public. After further advocacy, DHHS arranged for Ryan to move to interim accommodation, after more than one year in the respite house. This property was not robust (enabling it to be easily damaged), inadequately heated, too small to safely accommodate Ryan and his workers, and adjacent to a busy road (which posed a risk to him when he left unaccompanied). Nevertheless, Ryan's guardian felt they had no choice but to consent to the move because DHHS stated that it was the only option available for him. Ryan did not settle in this property and, within a couple of weeks, had returned to his parents' home. Reluctant to return Ryan to an inappropriate environment against his wishes, Ryan's guardian consented to two trials of living with his parents but both trials had to be terminated within a few weeks after Ryan assaulted his mother and caused serious damage to the property. Ryan continued to regularly leave the property unaccompanied by staff (and was hit by a car on one occasion), to assault staff and to damage property. He also attempted to break into another family member's home, spent four days in a mental health unit where he was subject to extended seclusion, and was discharged back to this accommodation without his guardian's approval. Throughout this time, Ryan's guardian continued to be told by DHHS that no appropriate alternative accommodation was available (although he had been considered for over 50 vacancies).

While in the DHHS property, Ryan became an NDIS participant and received his first plan, so DHHS closed its file for him. Ryan's NDIS plan provided for support coordination (a role taken up by the service provider which had been acting as case manager) and over ██████████ for 'core supports' including 2:1 day staff support and sleepover support at night. Ryan's guardian was not consulted in the development of this plan and considered it to be manifestly underfunded because there was no funding for a functional behavioural assessment, additional support workers at critical times nor enrichment activities. A plan review was requested for increased behaviour therapy and specialist support but this was refused by the NDIA, and Ryan was advised to wait a few months before requesting an increase in direct care funding.

Within a few months of the NDIS plan commencing, Ryan's support provider decided to withdraw its services on the grounds of staff safety. The intended new support provider was unable to commence for a few months and no interim support provider was able to be engaged, leading OPA to escalate crisis talks with DHHS and the NDIA. This led to Ryan's support provider agreeing to remain involved for a further two months and then a different support provider being engaged. It is noted that Ryan's support coordinator also tried to engage a behavioural support specialist to develop a new behaviour support plan and strategies for workers to better support Ryan, but, over the course of seven months, was unable to find a willing service provider due to the limited NDIS funding.

Ryan was subjected to a range of restrictive practices by his support workers. Ryan's guardian requested the involvement of the Office of Professional Practice, and the Senior Practitioner for Disability issued a direction under the Disability Act to the new support provider to cease the unauthorised chemical restraint and detention which they had been using against Ryan. OPA noted that it was difficult for inadequately trained and supported staff to provide effective support in a manner which respected Ryan's rights. It was not clear to OPA whether the Senior Practitioner's direction was followed.

Ryan's NDIS was plan was apparently reviewed again and funding significantly increased, including to provide for 3:1 support. The guardian never received a copy of this plan. However, after a period of funding at this higher level, the NDIA persuaded the support provider to drop back down to a 2:1 support model.

After seven months in the property, DHHS proposed that Ryan be moved temporarily to enable the damage to be repaired. Ryan's guardian refused to consent to this move because they considered that the proposed property was less safe. Ryan's support coordinator also considered that the proposed property was unsuitable and did not support the move, so the NDIA terminated the agreement with that support coordinator and engaged another one. Eventually Ryan's guardian consented to Ryan being moved for seven days, but he ended up being in that property for five weeks. Ryan's guardian inspected his primary accommodation and advised DHHS that there were still safety concerns. However, DHHS said that it was not responsible for those matters and, acting on DHHS' instructions, Ryan's support workers transferred him back to his property without his guardian's consent.

It was felt that the level of support available to Ryan under his NDIS plan was still inadequate and so the new support coordinator requested a plan review. Ryan received a new three-month plan, which provided about 40 per cent more funding pro rata than his first plan. It allowed for two active night support workers and enabled the support coordinator to engage specialist behavioural support. However, the NDIA planner indicated that, after three months, they intended to reduce funding for direct support to one daytime and one overnight worker. Ryan's guardian and others expressed concern that lowering the staffing ratio would be inadequate and would place Ryan at risk of assaulting workers and entering the community without support.

At this time, Ryan's guardianship order came up for review at VCAT. The guardian expressed concern that Ryan continued to remain in inadequate accommodation, had received inadequate care, was not exposed to opportunities for enrichment and development and had a poor quality of life. Aspects of Ryan's management had been investigated by the Victorian Ombudsman, the Disability Services Commissioner, Victoria Police and DHHS Systemic Improvement Practice Review during the course of the year but it remained unclear which, if any, agency had responsibility for implementing any recommendations. The guardian noted:

*The transfer of responsibility from DHHS to NDIS has proved to be a transfer from a case management model with "ownership" of issues to an "insurance" model with ill-defined roles and responsibilities among service providers. The current NDIS funded system is ill-equipped yet to deal with high levels of complexity... There currently appears to be confusion about which agency identifies, locates and maintains accommodation.*

Ryan's guardian argued that the systemic issues over the preceding year had meant that no accommodation options had been presented to them for consideration during the year other than unsatisfactory and non-negotiable responses to crises, thus rendering guardianship futile. They suggested to VCAT that OPA would be better able to support Ryan as an advocate. VCAT, therefore revoked the guardianship order and requested that OPA continue to provide "strenuous advocacy" for Ryan.

A few months later, it was alleged that staff from Ryan's support provider had assaulted him. This support provider received a notice of deregistration and was removed. The support coordinator sought to engage an alternative support provider, but the preferred provider needed to recruit more staff before they could commence providing services to Ryan. So, in the absence of any alternative options, Ryan's initial support provider was reengaged on an interim basis, despite their inability to manage his support appropriately in the past.

A few weeks later, before the preferred support provider had come on board, Ryan was charged by police after he left his house unaccompanied and assaulted members of the public. At this point, he was bailed back to his property. Lack of stable and competent support likely contributed to the

conditions which led to Ryan assaulting a member of the public on a subsequent occasion the following month. This time, he was remanded into custody – his first time in custody. His support provider withdrew their services at this time on the basis that Ryan posed a business risk. This meant that Ryan could not make a viable application for bail. Ryan’s psychologist summed up the trajectory that led to him being remanded:

[Ryan] has faced significant instability in the past 12 months, and this has resulted in severe behavioural disturbance, and him being unlawfully detained in his residential setting... to end up in custody for lack of other options would be inhumane and a further injustice.

It was widely acknowledged by all parties that, if Ryan had accommodation and a support provider in place, a grant of bail would not be opposed and, further, if he was able to enter a plea to charges, he would only receive a low-level, non-custodial sentence. However, Ryan was considered to be unfit to be tried which prevented a speedy resolution of the case. Ryan’s support coordinator struggled to recruit a willing support provider to provide supports to Ryan in the community. Those that did express initial interest had little background working with people with complex needs and no staff cohort with relevant experience or training. Ryan’s lawyer sought assistance from OPA and the Office of Professional Practice to press DHHS to help source appropriate accommodation and a support provider to enable Ryan to be bailed.

At this time, DHHS appeared to view itself as just one of a range of accommodation providers, with no particular obligation towards Ryan. After being subpoenaed to give evidence, DHHS advised the court that it had no accommodation available for him and that it was not responsible for finding alternative accommodation or supports because Ryan was an NDIS participant, so supports should be located by his support coordinator and funded by the NDIA. Ryan’s support coordinator gave evidence that they were unable to fulfil a traditional case management role and had been unable to engage a competent support provider; the preferred support provider was still unable to commence for another few months. They also expressed the view that the current model of support was not adequate and that Ryan required allied health-level, trained professional workers rather than low-skilled disability care workers.

OPA held significant concerns for Ryan in custody, noting that he had been handcuffed for transport to court hearings and was likely subject to physical restraint and coercion. He was extremely isolated and had to wear a spit-mask each time he left his cell. He was very distressed by his experience in custody.

Following another review, a new 12-month NDIS plan was approved, which increased Ryan’s funding [REDACTED]. By this stage, it was clear that the quantum of funding was not the barrier to engaging a service provider.

The support coordinator entered negotiations with another support provider to provide interim services for a few months until the preferred provider could commence. However, the intended interim support provider then withdrew, again leaving Ryan without any viable plan for bail. By this stage, he had been in custody for three months. In desperation, his parents, supported by his lawyer, reached out to the media about his situation. During the media coverage, the Victorian Minister for Housing, Disability and Ageing stepped in and secured agreement from a suitably experienced support provider.

Soon after, Ryan was granted bail but, upon arrival back at his former residence (the site of his alleged abuse by former support workers), he allegedly assaulted two staff members. Initially, the police said that they were not planning to arrest Ryan or take him back into custody. However, half an hour later, the support provider withdrew, which meant there was no-one to provide Ryan with the residential supports he required. In these circumstances, the police charged Ryan with a minor assault and he was taken back into custody.

Months later, DHHS located yet another support provider to work with Ryan. However, that provider said that they would not be ready to start working with him until the following month. It was

also clear that Ryan needed more appropriate accommodation in the community. Because of the dearth of disability housing stock, Ryan had to wait for residents of an existing DHHS property to be moved out, and then for substantial modifications to be completed to that house. The new support provider then applied to VCAT for a supervised treatment order (STO) under the Disability Act, which authorises Ryan's detention and other restrictive interventions to be applied to him in the property. Once the STO was in place, Ryan was finally granted bail again – [REDACTED] after he was remanded. The charges against him were later withdrawn.

Ryan's modified property is extremely restrictive: he is unable to leave the house and there are physical barriers completely separating him from his workers. The intention is to stabilise his situation sufficiently to allow proper professional assessment and therapeutic engagement. The behavioural support specialist has done some work with Ryan's workers but has yet to engage with him directly. Progress is extremely slow, as it to be expected given the disruptive and traumatic circumstances Ryan has had to endure over the last few years, and OPA remains uncertain whether the arrangement will ultimately prove effective for him.

## Con's story

Con is a young man who has been diagnosed with schizophrenia, an intellectual disability and, more recently, with autism spectrum disorder. He has been receiving mental health services for well over a decade. He cycled between the local hospital mental health unit, a community-based mental health rehabilitation facility, SRSs, motels and other forms of inadequate accommodation for some years, often causing a deterioration in his mental health and leading to self-harm. Because his local mental health service does not have its own SECU, he was admitted to a bed it controls in a SECU [REDACTED]

The comparative roles and responsibilities of Con's original mental health service and the SECU are somewhat unclear. The social worker at the SECU was concerned that the original mental health service would seek to discharge Con, without suitable supports having been arranged, so that it could place other patients in his SECU bed. This prompted it to apply to VCAT for a guardianship order. Clinicians from the original mental health service confirmed that there was pressure 'from above' for them to discharge Con due to bed pressures.

An investigation by OPA in relation to the guardianship application found that, for at least the last 12 years, the approach to Con's treatment and support had been solely predicated on his mental illness diagnosis and had largely ignored the impact and requirements of his other disabilities. Discharge planning has also been complicated by Con straddling the two catchment areas and by silos between the mental health and disability service systems. Con apparently cannot be discharged to any accommodation or services near the SECU because he is not from that catchment (notwithstanding he has no fixed address in his original catchment and has not resided there for some years). He is often targeted with bullying behaviour by co-patients in the SECU and an autism specialist who diagnosed Con advised that disability services, rather than the mental health system, would provide more appropriate accommodation and support to meet his needs. However, both mental health services have admitted that they are unfamiliar with what disability accommodation and services may be available to Con. [REDACTED] were involved to try to help the [REDACTED] mental health services communicate and explore options, but their involvement stalled and they have disengaged.

Following the investigation, OPA was appointed as guardian with decision-making authority in relation to accommodation and access to services. Four months later, a clinician from Con's original mental health service notified OPA that Con had been discharged to the mental health rehabilitation facility in his original catchment a few weeks ago. During the investigation, Con's mother had described his last stay in this facility as disastrous and had been very worried about the prospect of him being readmitted there. When OPA expressed concern that it had not been consulted about nor approved this move, the clinician stated that the decision to relocate Con was a medical decision.

The NDIS rolled out in Con's original catchment [REDACTED] and in the SECU location [REDACTED]. OPA has not been advised when Con was first referred to the NDIS but it is known that he is on at least his second NDIS plan. According to the SECU social worker, Con never used the services funded in his previous NDIS plan(s) because they were inappropriate. Since his NDIS package was increased following his autism diagnosis, disability support services were engaged to provide some support to Con in the SECU, which was apparently helpful. It is unclear whether he is continuing to receive that support in the mental health rehabilitation facility. Five years after Con potentially became eligible for the NDIS, it appears that his current NDIS plan is still inadequate to enable him to be appropriately supported in the community and to overcome the systems barriers and lack of suitable accommodation that contributed to his lengthy detention. It is hoped that, with further advocacy, his NDIS plan will be expanded following his upcoming plan review to enable some positive steps forward.

## Abbreviations

CCU	Community Care Unit
DHHS	Department of Health and Human Services (Victoria)
Disability Act	Disability Act 2006 (Vic)
ISP	Individual support package
IST	DHHS Intensive Support Team
ITP	Independent Third Person
MACNI	Multiple and Complex Needs Initiative
Mental Health Act	Mental Health Act 2014 (Vic)
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDIS Act	National Disability Insurance Scheme Act 2013 (Cth)
ODSC	Office of the Disability Services Commissioner
OPA	Office of the Public Advocate
SDA	Specialist Disability Accommodation
SECU	Secure extended care unit
SRS	Supported Residential Service
STO	Supervised treatment order
VCAT	Victorian Civil and Administrative Tribunal

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