**Ten stories of NDIS ‘Thin Markets’: Reforming the NDIS to meet people’s needs**

**Submission to the Department of Social Services and the National Disability Insurance Agency’s *NDIS ‘Thin Markets’ Project***

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Written requests should be directed to Victoria Legal Aid, Research and Communications, Level 9, 570 Bourke Street, Melbourne Vic 3000.

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# Executive summary

Victoria Legal Aid (**VLA**) welcomes the opportunity to contribute to the Department of Social Services and National Disability Insurance Agency’s *NDIS ‘Thin Markets’ Project* (**Project**).

We have joined with the Northern Territory Legal Aid Commission and Legal Aid Queensland to present the stories of 10 people from across Australia whose lives and wellbeing have been affected by ‘thin markets’.[[1]](#footnote-1)

Their stories highlight ‘thin market challenges’ across the country and, importantly, remind us that ‘thin market challenges’ have very real consequences for people, their families and the communities around them. These include:

* Extended detention in mental health services
* Prolonged periods in custody without conviction
* Inability to obtain bail or parole
* Homelessness
* Deterioration in health, wellbeing and social engagement
* Increased risk of offending or re-offending
* Family breakdown, including through the child protection system.

Of the 10 people whose stories we share, seven are living in regional or remote areas, six are young people, two are experiencing homelessness or at risk of it, and four spent protracted periods in jail or a mental health unit that could have been avoided with the right housing and supports in the community.

The NDIS continues to be a source of optimism and promise for Australians with disability. In its current form, however, it has added another layer to an already complex system, it has created or widened gaps in services, and, in some cases, it is exacerbating rather than resolving problems for people and their families.

‘Thin markets’ – where people cannot get the services they are funded to receive – are one of the significant reasons that the NDIS is not yet living up to its promise of giving choice and control to Australians with disability.

In its current form, the NDIS cannot adequately cope with complexity: complexity of needs, complexity of behaviour and complexity of location. Australia’s system for meeting the needs of people with disability can – and must – do better than this.

We commend the DSS and NDIA for initiating this Project. We are pleased to have been able to contribute evidence from our casework, including the stories of 10 clients of Legal Aid Commissions across Australia. We look forward to continuing to work with the NDIA, the State, Territory and Federal Governments and our partners in the community and legal assistance sectors to resolve these priority issues and maximise the potential of the NDIS for our clients and the community.

We encourage the NDIA to seek out and learn directly from people with disability, both NDIS participants and those who have been found ineligible for NDIS supports, so that their experience can inform scheme design and reform.

# Six priorities for responding to thin market challenges

Informed by our work with clients who are, or should be, NDIS participants, we set out six priorities for responding to thin markets.

1. **Planning that sets people up well from the outset**

In many of our clients’ cases, a lack of appropriate planning at the outset of their participation in the NDIS meant they were not set up with the supports they needed to live well and independently. Their disability needs were not well met and the intensive core supports they needed were not funded, which put pressure on the services that were funded and created a risk of those services withdrawing.

Equipping, resourcing and overseeing skilled planning, that facilitates supports that are appropriate to the particular person and their needs, is critical to the effectiveness of the NDIS.

1. **A workforce and system that can engage with complexity**

For clients with complex needs and behaviours of concern, innovative, skilled support coordinators are an essential part of the NDIS regime.

A common theme that arises across VLA’s work with people who are – or should be – engaged with the NDIS is the lack of systemic coordination. It is inherent to the design of the NDIS that no one agency or worker is responsible for a person’s supports and for navigating the system, which most significantly affects people who face additional barriers to doing that themselves. Similarly, when we observe the system working well, the common factor is skilled coordination by someone with a strong knowledge of the system.

Skilled and experienced support coordinators must be a systematised and ongoing part of the scheme for people with complex needs (not just as an introductory requirement) to problem-solve issues, navigate systems and think creatively about supports. This is a key foundation for keeping other supports in place.

1. **Choice and control for people in rural and regional communities and access to culturally safe services**

Seven of the clients whose stories are featured in this submission live in regional or remote areas.

It is clear that people with disability in regional and rural areas continue to be disadvantaged by the roll-out of the NDIS. As the stories from the Northern Territory show, this is severely impacting upon access to the NDIS by Aboriginal and Torres Strait Islander people and communities.

Training, engagement and capacity building for local services, changes to pricing and guidelines in relation to travel for providers and participants, and – if needed – directly purchasing services on behalf of participants, should be implemented as a priority to make sure that realisation of the promise of the NDIS is not confined to our cities.

1. **A planned approach to people in prison or inpatient units**

In the absence of proactive discharge and pre-release planning, discharge or release can be (a) delayed, causing people to be stuck in prison or mental health inpatient units; or (b) ineffective, because poor planning or subsequent market failure means a person exits with inadequate supports and is more vulnerable to re-offending or readmission.

Staff in prisons do not have the required skills, systems or supports to assist people to apply for the NDIS and whether or not they are responsible for doing this is approached differently across the country. While this is an issue of access, it is also a systemic issue, and a market-based issue in that people in prison are effectively a specialised group or ‘market’.

People who remain in custody or mental health units because of a failure to secure disability services should be identified by the NDIA and State and Territory Governments as a matter of urgency.

Clear processes for planning for a person’s release before their sentence is complete or discharge is imminent should be systematically introduced so that supports are in place to facilitate successful discharge or release and reduce risk of reoffending or readmission. This may also require the funding of supports for transition prior to release.

1. **Using pricing as a lever**

While pricing is not the only driver of thin markets, it is a relevant factor in the difficulties our clients have securing the supports funded in their plans. Pricing should contemplate the costs of delivering supports to people with high and complex needs, as well as the costs of delivering supports in regional and remote areas.

1. **A service safety net that is responsive, accessible and has clear accountability**

The disability system must ensure that people will get the services they need even when the NDIS market is not working as it should.

As this submission shows, for some people with disability, at this stage of the NDIS’s lifecycle – and potentially for the longer term – the market cannot be relied on to meet their needs and, where it fails, the consequences are too significant to overlook.

Thoughtful research and consultation are crucial, however, while this takes place and while the NDIS evolves, it is imperative that a reliable, systematised framework of accountability, coordination and response is in place in every State and Territory.

If a person has been found eligible for the NDIS and has a funded plan but cannot secure supports for reasons related to the market or the support provider withdrawing, the NDIA or other government agencies must intervene to ensure that the person with disability does not bear the burden of this system failure. It must be clear (including to the public) who is responsible for arranging, funding and providing services in these situations.

This is essential to making sure people do not slip through the cracks and end up in prison, in the mental health system, or separated from their families.

# Victoria Legal Aid, our clients and the NDIS

VLA is an independent statutory agency responsible for providing information, advice and assistance in response to a broad range of legal problems. Working alongside our partners in the private profession and community legal centres, we help people with legal problems such as criminal matters, family separation, child protection, family violence, fines, social security, mental health, immigration, discrimination, guardianship and administration, tenancy and debt.

Our Legal Help telephone line is a resource for all Victorians to seek information, advice and assistance with legal problems. We also deliver specialist non-legal services, including our Family Dispute Resolution Service, Independent Mental Health Advocacy and Independent Family Advocacy and Support, as well as providing community legal education, and contributing to policy and law reform.

VLA is the largest provider of legal services to people with disability in Victoria. During 2017–18, we assisted 94,485 unique clients: 26% disclosed having a disability or mental health issue.[[2]](#footnote-2)

We offer a specialist legal service which provides advice and representation at courts, tribunals and psychiatric hospitals for people with disability and experiencing mental health issues.

Like all Legal Aid Commissions across Australia, VLA receives funding from the Department of Social Services to provide legal representation in NDIS matters on review at the Administrative Appeals Tribunal (**AAT**). Since 2013, we have provided legal representation to over 100 people with NDIS AAT appeals.

In addition to specialist work of Legal Aid Commissions with clients with disability, through our work across criminal law, child protection and family law, we see the flow-on effects when our disability services systems, including the NDIS, are not working at their best.

It is this work that has informed this submission and the priorities it identifies.

# The impact of ‘thin markets’ for people with disability, families, communities and the NDIS

As we set out above, of the 10 people whose stories we share in this submission, seven are living in regional or remote areas, six are young people, two are experiencing homelessness or at risk of it, and four spent protracted periods in jail or a mental health unit that could have been avoided with the right housing and supports in the community.[[3]](#footnote-3)

As these stories show, we continue to see the consequences of ‘market failure’ or ‘thin markets’ for our clients – particularly people with complex needs and people in regional areas – where service providers are not ready, willing or able to provide the services and supports a person needs to live well and safely in the community.

As Isaac’s story shows, at its worst, the transition to the NDIS is having long-term negative impacts on people’s mental health and wellbeing. People have lost access to services they previously had and are subjected to assessment processes that are stressful and damaging.

The immediate and long-term harm being caused, and the impact on people’s social and economic wellbeing, warrants urgent attention.

**Isaac: Teenager in regional area removed from family because of inadequate supports**

Isaac is 16 years old and lives with his family in a regional area. Isaac’s mother and stepfather also have five younger children, and he does not have a relationship with his biological father. Isaac has autism, and his family needs support – particularly respite – to manage his behaviours and minimise the impact on his siblings.

Isaac previously had access to weekend respite care supports and would participate in group activities such as fishing and camping with carers and other children. His mother says that this worked well. However, when Isaac transitioned to the NDIS these supports ceased as his NDIS plan specified 1:1 respite care, and the service provider was only able to provide this on weekdays.

To access this service, Isaac’s family was required to drive long distances between regional centres every day of the week – picking him up after school, dropping him off overnight, and then returning to collect him before school the next morning. Isaac’s family explained that this was unmanageable, but the service provider said they were required to comply with the NDIS support plan.

Without appropriate supports, Isaac’s behaviour became increasingly difficult and his mother and stepfather were concerned about the impact on their other children. His family instead attempted to manage the situation themselves by arranging for Isaac to live with his grandmother, and subsequently by renting a property so that Isaac and his stepfather could live there separately.

These arrangements were unsustainable and ultimately the family contacted DHHS seeking respite or shared care as Isaac’s behaviours became too difficult to manage without appropriate supports. In response, DHHS issued a protection application and sought a Family Reunification Order, which was granted in 2018. Isaac was initially placed with his biological father, but when this arrangement broke down, he was placed in a residential unit.

Isaac has formally been in a residential care unit since July 2018. During this time, he has stopped attending school, no longer works in his part-time job umpiring football and his mother states that he has experienced bullying by other residents. Over the last few months, Isaac has spent a considerable amount of time at home with his family, at one time spending 12 out of 14 nights in a fortnight with his family.

Despite this, DHHS has now made an application for a Care by Secretary Order. Isaac’s mother has sought an internal review of the case plan and is awaiting a decision. VLA has arranged representation for Isaac and his mother for the hearing, and has referred Isaac’s case to the NDIS Intensive Support Team for investigation.

Isaac’s case highlights the way in which thin markets can result in situations where everyone loses. In this case, Isaac, his family, the service provider and the child protection system are all worse off as a result of the NDIS market’s failure. There are compelling policy reasons for building a system that avoids these outcomes.

Although the inevitability of thin markets and market failure was anticipated in planning for the NDIS, and there have been a series of calls for urgent measures to address thin markets and market failure,[[4]](#footnote-4) there is still no enforceable obligation on any government body to ensure that an NDIS participant receives their funded support and no systematised way of avoiding and addressing thin markets and their consequences. We welcome the focus on remedying this.

# Guaranteeing a system that can engage with complexity

In seeking to understand the factors influencing thin markets, with a view to supporting the development of an equitable NDIS market, it is important to recognise that some participants’ needs are higher, and histories and behaviours more complex, than others. A number of VLA’s clients, for example, have histories of offending and imprisonment. Their disability can play a role in their behaviour and engagement, with some people needing 24/7 support by multiple workers.

These participants are more challenging and at present the NDIS market is not ready to meet their needs.[[5]](#footnote-5) As the Office of the Public Advocate noted in the 2018 report, *The Illusion of ‘Choice and Control’*:

*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.*[[6]](#footnote-6)

We encourage the Project to look beyond geography and pricing in contemplating why the market is not stepping in to meet the needs of all people with disability.

It must not be the case that people who are ‘less desirable’ for the market are unable to get services to live well and safely in the community. This is an inherent risk of the scheme and one that must be proactively addressed.

# Getting services right from the outset to minimise the risk of market failure

Where people with disability do not have skilled assistance to apply for the NDIS and assess supports, the funded services they receive may not adequately respond to the person’s needs.

By way of example, we have worked with a number of clients with complex support needs, including as a result of intellectual disability, autism spectrum disorder or psychosocial disability, combined with experiences of homelessness and offending, who have received plans that cover only activities such as weekly bowling or cooking, rather than more intensive core supports.

If a person’s disability needs are not well met and the intensive core supports they need are not funded, this puts pressure on the services that are funded and creates a risk of those services withdrawing.

In John’s case (set out below), his plan initially included nine hours of core supports, which were largely consumed with taking John to multiple weekly appointments. Without more intensive supports in place, he committed further offences and was taken into custody. He was unable to secure housing or bail and spent 10 months in prison. His ability to access post-release housing and supports was affected by the complexity of his needs and delays in plan review. Eventually, after his plan was reviewed by a worker with greater experience and skill in relation to John’s disability, his NDIS funding was increased to cover more intensive services, including 24/7 support.

**John: Inadequate planning and services contributes to offending and homelessness**

John has an ABI and schizophrenia, and his disabilities have contributed to past substance abuse, lack of employment, and limited community engagement. He has a history of offending, most commonly at the lower level. His disabilities have a significant impact on John’s everyday functioning. His housing has been unstable, and his behaviours of concern make his housing options limited. John has been most successful in retaining accommodation and reducing recidivism when he has received consistent supports both at his accommodation and during outreach.

**NDIS-funded supports and offending**

John’s NDIS plan initially included only nine hours per week of core supports for him, which were largely absorbed by taking John to and from multiple weekly appointments. This meant that John’s support provider did not provide support for John to engage in daily activities of his choice, or provide opportunities for him to be active and safe in the community.

Without more intensive supports in place, John committed further offences and was taken into custody.

**Cycling in and out of court and prison**

After being taken into custody, John appeared before the Magistrates’ Court. At the same time, he became homeless. John’s NDIS providers did not attend Court to provide information about John’s needs or what services they provided to him. John was provided short term accommodation for four nights at a motel and he was bailed to this address.

John had individual nights of accommodation in emergency situations. He spent weeks sleeping rough, in emergency departments or at his father’s house in breach of a current IVO.

After re-entering custody, John remained in custody on remand for seven months, and applications for bail for John were adjourned and then withdrawn because of the absence of suitable accommodation in the context of his minimal supports. Community housing providers and the Victorian DHHS could put John on their waiting lists, but these lists did not guarantee housing and it was also recognised that this housing was unlikely to be sustainable for John without intensive daily support.

**Escalation to Victoria’s Intensive Support Team**

VLA had been unsuccessful in encouraging John’s support coordinator to push for a review of John’s plan in light of his crisis situation and the inadequacy of his funded supports in meeting his needs.

VLA escalated John’s case to the DHHS Intensive Support Team in Victoria. This team began working in a coordinated way with the multiple people and organisations engaged with John. The team liaised with VLA to progress accommodation and support options with reference to the criminal trial process timing, bail hearings, upcoming mentions in the matter and effectively ‘stepped in’ for a period of time to provide a central, coordinating, and solution-focussed role at the justice interface.

**The benefits of expert planning and coordination**

John’s existing plan was ultimately considered by a new specialist support coordinator with established expertise working with people with complex needs.

This support coordinator worked with a Victorian Supported Residential Service to identify a creative accommodation solution which would see John share a two-bedroom unit with a previous co-resident who he had maintained a good relationship with. The Supported Residential Service advised that it could not work with John if his funded supports remained minimal, but were happy to hold this accommodation to allow the pre-release planning to occur.

**Tension between NDIA and mainstream services**

A new NDIS planner was allocated to John’s case just before his hearing date and indicated a further three months would be needed to assess the information and make an informed decision. This planner also raised concerns regarding the references in evidence to both John’s offending and his disability support needs. There was some indication that funding for supports to meet John’s complex needs might be refused because of their relationship with reducing his risk of re-offending (because this was seen as a justice issue).

VLA again escalated John’s case with the DHHS Intensive Support Team, noting that John was facing further unnecessary time in custody if his pre-release planning was delayed. The Intensive Support Team contacted the NDIA and arranged for the planning to be promptly undertaken.

VLA lawyers worked with the Court and prosecution to obtain a new hearing date for the matter. The plan review was completed and John’s supports were increased to provide 24/7 support for him in his home. These supports made the shared accommodation option feasible for John in circumstances where previously his disability had made shared accommodation options impossible to maintain.

John’s situation – including the plan review and securing services and supports to build a sustainable post-release pathway – took 10 months to resolve. For the majority of this time, John was in custody.

The capacity to equip and resource skilled planning that facilitates access to supports appropriate to the particular person and their needs, is critical to the effectiveness of the NDIS.

In the absence of skilled planning, the supports people do have are more likely to fail, exacerbating the already thin market of people with complex needs.

#  A workforce and a system that can engage with complexity

Samantha and Jenny, both living in regional areas in Victoria and both with different complex needs and circumstances, were facing severe hardship for themselves and their families stemming from their NDIS funded services being unavailable.

Both their situations were eventually resolved favourably and, as a result, their stories highlight the enormous difference in outcomes when the workforce and the system is able to engage with people with complex needs and circumstances, compared to when it is not.

In Samantha’s case, her parents were forced to fill the gaps when carers with necessary specialist training were unable to attend rostered shifts. Inconsistent care arrangements had a devastating impact on Samantha and her family, putting at risk their physical, financial and emotional wellbeing.

**Samantha: Overcoming thin markets for a child with complex support needs and her family**

Samantha has multiple, complex disabilities. She is seven years old. She loves Peppa Pig, playing with playdough, cars, baby dolls, bubbles and listening to stories. She lives in a regional centre with her family. Samantha’s disabilities can result in multiple seizures each day, low muscle tone and serious respiratory vulnerability.  Samantha’s disabilities mean that she can’t mobilise without assistance and she needs to be constantly watched to determine if she is having a seizure, how severe the seizure is and the appropriate medical response.  Samantha’s treatment and the medical responses to her disabilities have been determined by a major teaching hospital.

During her first four NDIS plans Samantha had access to a small number of carers who received the specialist training required to safely care for her. Her care agency often cancelled shifts because no trained carers were available, or because carers were unwell. Samantha is at risk of hospitalisation if she gets an infection. In their place, Samantha’s family attempted to fill the gaps.

This market failure was created by an inadequate pool of trained carers and a lack of a back-up mechanisms for Samantha in her regional area.  The personal and financial impact on Samantha’s family was extreme.  On several occasions, her father cared for her for 36 hours without sleep. When Samantha’s family members got sick they faced a choice between trying to care for her with the risk of infection and failing to care for her. At times her father was only able to work one day per fortnight because he was caring for Samantha during gaps in the roster and responding to emergencies when existing staff quit or called in sick for shifts. Samantha’s family had to rely on another family member for financial support as they couldn’t work full-time.

VLA took on Samantha’s case in the Administrative Appeals Tribunal (**AAT**). The AAT decided, contrary to the position of the NDIA, that the NDIA should pay for Samantha to receive care from nurses when her care agency cancels shifts at short notice and her parents can’t care for her because of their work. This back-up mechanism meant that Samantha was guaranteed access to trained carers during all rostered shifts, allowing her parents to work and also be assured of their daughter’s safety.

In the case of Samantha and her family, the AAT appeal process ensured access to safe and specialised support when the market failed. This should not be necessary. Instead, we should be able to expect better decision-making as part of the NDIS, with market stewardship by the NDIA to avoid the strain caused by this thin market.

In Jenny’s case below, the service providers in the local market initially refused to provide services in the home, which contributed to a risk of eviction. However, once a problem-solving housing worker addressed the source of the concern, these services were able to commence and the family could maintain their housing.

**Jenny: Mother and her daughters avoid eviction**

Jenny is a mother with a physical disability who lives with her adult children, Kylie and Anna. The family live in public housing in a regional area. Kylie and Anna have disabilities and NDIS plans. The family was finding it difficult to keep the property clean due to a deterioration in Jenny’s health and the nature of Kylie and Anna’s disabilities. When VLA took on Jenny’s case, the family unit was facing eviction due to concerns about the property’s cleanliness. This presented a very real risk of homelessness and break-up of the family.

Kylie and Anna’s NDIS plans included funding for cleaning supports, however this funding was not being used. VLA contacted Kylie and Anna’s NDIS support coordinator and asked for their help to engage a local service provider for cleaning support. The service provider initially refused to provide cleaning support due to concerns about safely accessing the property. Luckily, a social housing advocacy agency obtained funds to allow the house to be cleaned to the extent the service provider could access the property. As a result, the family now has access to weekly NDIS supports to clean the property. Six months on the family has not been evicted, in large part because of their access to these NDIS supports.

In both Jenny and Samantha’s situations, the market’s initial inability to engage with complexity was putting both families at risk. This was rectified through an AAT appeal in one case, and addressing the concerns of the provider with the house so they could commence regular service provision in the other.

In the case of VLA’s client Francis, who spent 180 days in jail because his NDIS funded accommodation and supports failed, the consequences of services withdrawing for clients with complex needs are difficult to overstate. In reviewing Francis’s situation, Justice Lasry said:

*‘He’s in 23-hour lockdown at Melbourne Assessment Prison. I can’t imagine a worse place for him. The longer he is there the more he will be damaged. Who knows what damage has been done already?’*[[7]](#footnote-7)

The NDIS must not lead to a disability services system that caters only to people whose needs are easy or convenient, leaving others behind to experience hardship, homelessness or incarceration.

# Delivering choice and control for people in rural and regional communities

It is increasingly apparent that people with disability in regional and remote areas face a real risk of not being able to access supports due to a lack of available services and/or an inability to access suitable services.

As this story from the Northern Territory highlights, market deficiency is even more acute for remote Aboriginal and Torres Strait Islander communities.

A concerning cycle of service reduction has also been identified whereby:

1. A person is unable to access funded supports, due to a lack of available or culturally sensitive services;
2. As a result, funding included in the NDIS plan is underspent;
3. Consequently, funding in subsequent NDIS plans is reduced.

The below stories from Legal Aid Commissions across Australia demonstrate this very real and disproportionately borne problem.

**Jade: Absence of NDIS service providers contributes to entry to the justice system**

Jade is a young child who was assisted by NT Legal Aid in proceedings before the AAT. Jade lives in a highly remote area in the Northern Territory and has significant disability support needs.

Due to there being no service providers in the region, the allocated funding in Jade’s first NDIS plan was not fully utilised. On this basis, the funding approved in Jade’s subsequent plans was reduced significantly, leading to the cessation of necessary behavioural supports. Without these supports, Jade had encounters with the criminal justice system.

While NT Legal Aid’s advocacy led to an overall increase in funding for Jade, it was not to the level provided in Jade’s first plan, or to the level arguably required to provide adequate support. A thin (or in this case, absent) market had already led to poor legal outcomes for a child.

**Zachary: Young child in a remote community missing out on services**

Zachary is four years old. He has a rare genetic disorder that manifests in both physical and intellectual impairments. Due to his age, the provision of early childhood intervention, physiotherapy, occupational therapy, psychology and support in the home and community is critical.

Zachary lives in a remote community in Queensland, and his mother is required to travel over 800km each week to take Zachary to the closest regional town, city and metropolitan city for medical appointments, assessments and therapy services. The funding in Zachary’s current NDIS plan does not include any allowance for travel time or for the provision of support workers to assist Zachary at home.

Zachary’s parents are physically and emotionally exhausted and this current arrangement is unsustainable. They have commenced a review in the AAT regarding the adequacy of the supports in Zachary’s plan, but even with the support of a disability advocate and a Legal Aid Queensland lawyer, it is anticipated that securing funding for travel time or for support workers to assist Zachary at home will be a challenge.

**Beau: Removal of choice in access to respite services has serious consequences for young man and his family**

Beau is a 22-year-old NDIS participant living in regional Victoria with Down Syndrome.

He was adopted as a baby and lives with his mother in a regional centre with five younger children, some adopted and others fostered by his mother, including very young babies. Some of his foster siblings also have significant disabilities.

Beau’s disability means that he attends a full-time independent living day program between 9am and 3pm on weekdays and has done so since he turned 18. He calls his day program “work” and loves going there. Beau has a girlfriend who also has a disability and he spends time with her once a week, either at his home or at hers. Beau collects and watches DVDs and he loves Power Rangers and wrestling videos. He also plays drums and harmonica in his church band.

Beau needs constant supervision to avoid putting himself at risk of harm. He can do some things by himself but needs help with personal care and a lot of day to day living needs.

Since the age of seven, Beau has accessed regular respite services approximately once a fortnight to give both Beau and his mum a break from the home environment. From the age of 16, Beau has mainly used a DHHS facility called Street[[8]](#footnote-8) in his regional home town as his respite provider.

Because Beau has gone to the same respite facility so regularly, he’s grown up with the same group of boys who also have significant disabilities. Beau considers Street his home away from home. He has made some close friends among the other boys and Street is only place he gets to socialise with these friends.

Beau’s initial NDIS Plan allowed Beau to use “in kind” funding to continue going to Street for respite although the number of nights he could go there was reduced from his average 72 nights per year to 60 nights.

Unfortunately, in Beau’s second NDIS plan, this “in kind” funding was significantly reduced from 60 nights to 24 nights. The NDIA told Beau that he could use other “flexible funding” in his core supports to access respite service providers if he needed to.

However, in Beau’s regional town there are only two viable respite service providers for him and the NDIA’s decision to significantly reduce “in kind” funding meant that Street, Beau’s preferred respite facility, wasn’t available to him.

Beau’s mum noticed an immediate deterioration in Beau’s behaviour when he couldn’t keep going to stay at Street. He became aggressive and would have tantrums that took hours to abate. Beau began to assault his mum and his behaviour was very distressing for her and his younger siblings. His siblings became scared of Beau and so his GP prescribed a significantly increased dose of anti-depressants to try and manage Beau’s moods.

Beau’s mum needed to have more respite from caring for him, not less. She noticed that her health was declining which put at risk her ability to not only care for Beau, but also his other siblings and the foster children she has taken into her home. She became very overwhelmed at the thought of having to give up caring for Beau.

She made a statement to Beau’s lawyer that was used to advocate to get a better outcome for him at AAT review which included the following comment: “*I want [Beau] to be happy. At [Street], [Beau] is getting the benefits of both the peer-to-peer socialisation and skills for independent living which I regard as very important for him. [Beau] is able to express what he wants and he wants to go back to staying at [Street] every fortnight or so like he was doing. That makes him happy. If [Beau] is happy then it rolls onto us as a family. I think his wishes should be given priority*”.

VLA was able to advocate for an outcome by consent with the NDIA which reinstated most of the funding previously withdrawn although the litigation process in the AAT was unnecessarily drawn out and very hard on Beau and his mum.

Beau now has 54 nights of funding for him to keep using Street for regular respite weekends. He can socialise with his close friends once again and his problematic behaviours with his family have abated.

The restriction on Beau being able to access “in kind” funding to stay at the respite service of his choice resulted in a complete loss of choice because of the scarcity of specialist respite services in regional Victoria.

Beau’s story demonstrates the importance of choice for NDIS participants in accessing a preferred service provider able to meet their disability support needs.

Jade, Zachary and Beau’s stories highlight the current toll being taken on people with disability and their families in regional and remote communities, and the flow-on consequences for individuals, communities and the system. These thin markets represent a weakness in the NDIS that was predicted and which has been allowed to continue, unaddressed, to cause severe hardship and disadvantage to regional and remote communities.

# Planning and supporting successful pathways back into the community from prison or mental health units

People with disability face ongoing challenges with discharge and release planning from prisons or inpatient units. In the absence of proactive discharge and pre-release planning, discharge or release can be (a) delayed, causing people to be stuck in prison or inpatient units; or (b) ineffective, because poor planning or subsequent market failure means a person exits with inadequate supports and is more vulnerable to re-offending or readmission.

Discharge and release planning (whether it is from custody, a secure extended care unit (**SECU**) or another restrictive environment) requires earlier engagement and an awareness of the multiple ways that exit from a SECU, custody and remand can happen.

In Victoria, approximately 40% of the prison population is on remand. This proportion of unsentenced prisoners is growing as a result of recent changes to bail laws. This means more people are exiting custody abruptly, making discharge planning very difficult. Slow and inflexible NDIS planning processes also operate poorly within this system.

Last year, the Victorian Ombudsman tabled her *Investigation into the imprisonment of a woman found unfit to stand trial* in the Victorian Parliament. She described the imprisonment of a VLA client, a 39-year-old woman with a significant developmental disorder, as ‘the saddest case I have investigated in my time as Ombudsman’.[[9]](#footnote-9) The judge in Rebecca’s case said she might have been sentenced to a month in prison if she had been able to plead guilty and been sentenced for the charges. Instead, she was in prison for 18 months. Rebecca would have been released if she had housing and supports in the community. As the Ombudsman said, ‘[s]he remained in prison simply because there was nowhere else for her to go’.[[10]](#footnote-10)

The NDIS is a potential source of optimism and may be able to help fill some of the gaps in disability accommodation and services. In its current form, however, it has added another layer to an already complex system, and in some cases is exacerbating rather than resolving problems. Discharge planning for NDIS participants commonly requires coordination of multiple agencies, increasing confusion and diminishing accountability. Legal Aid lawyers, even those very experienced in coordinating services for bail applications, no longer know who to contact or how to undertake this process. Coordinating exit from custody for a person with disability often now requires the input of significant organisational resources of VLA and other government and government funded agencies.

The stories of Sam, Thomas and Joseph show the importance of planning for a person’s release before their sentence is complete or discharge is imminent so that supports are in place to facilitate successful discharge or release and reduce risk of reoffending or readmission.

**Sam: Young man in an acute psychiatric ward because he has no housing or services in the community**

Sam has spent over two years in an acute psychiatric ward of a public mental health service, despite not requiring inpatient treatment. Sam has Huntington’s disease – a neurogenerative disease which is terminal and can lead to complex support needs and behaviours of concern.

His successful discharge from the health service relies on a delicate balance of housing and supports, which span across NDIS and mainstream services. There are questions, for example, about whether Sam is eligible for Specialist Disability Accommodation (**SDA**) funding, and what packages of State-based and Federal funding could be combined to build durable housing and support options for him.

For over two years Sam has been confined to a restrictive environment which is not designed for his care because he does not have housing, is not funded to receive SDA (meaning that neither State nor Federal options are realistically available), and has not been the subject of any overarching consideration of what supports could be provided across the NDIS/mainstream interface to create a pathway out of the psychiatric ward.

Recently, VLA escalated Sam’s case to the DHHS Intensive Support Team. *The Age* reported that the Victorian Minister has ‘directed the department to prioritise finding suitable accommodation options’ for Sam. [[11]](#footnote-11) It was also reported that the NDIA reiterated that state and territory governments remain responsible for providing affordable and accessible housing to the community, including people with disability.

**Thomas: Market not open for people in prison**

Thomas is a young man who VLA assisted through 2018–19. Thomas has a significant psychosocial disability and has not previously received disability services in Victoria. In early 2018, Thomas was arrested for offending which is connected to his disability. His matter was finalised this year, with the outcome that he is now subject to a custodial supervision order made under the *Crimes Mental Impairment and Unfitness to be Tried Act* 1997 (Vic) (**CMIA**).

Until this order was made, Thomas remained in prison. Intractable planning, access, and intergovernmental coordination issues prevented him from making successful access requests to the NDIS and obtaining supports which may have had the potential to support his reintegration into the community through an application for bail, or a less restrictive resolution of his matter under the CMIA.

At multiple points in the process, VLA attempted to understand what established process there was for Thomas to be considered for the NDIS and to progress a request for access. The Court, too, repeatedly asked what NDIS supports would be available for Thomas if he was released from custody. During the process however, there appeared to be no trigger for access requests or planning to be commenced within the prison system. No entity was responsible or aware of Thomas’s NDIS status. In addition, as Thomas is a person with psychosocial disability, he was not already ‘on the radar’ of the Victorian DHHS because his mental health issues did not fall within the scope of State disability services.

Thomas’ ability to obtain access to the NDIS and commence pre-release planning fell away as responsibility and accountability for progressing his access request and planning was again dispersed through the NDIA and multiple State agencies.

**Joseph: Young boy from remote Northern Territory community cycles in and out of detention without NDIS supports in place**

NT Legal Aid recently assisted young people detained in the Alice Springs Youth Detention Centre and Don Dale Youth Detention Centre with their NDIS claims.

Significant difficulties in gaining access to the necessary specialist assessment services as a detainee caused lengthy delays in progressing the status of these claims. This delay often meant that the young person cycled out of detention and back into the community without any decisions being made with regard to their claim.

For example, Joseph is a young person who is currently detained in Alice Springs Youth Detention Centre who has been diagnosed with Foetal Alcohol Spectrum Disorder (**FASD**) and intellectual disability. As Joseph lives in a remote area of the Northern Territory, he was not diagnosed or formally assessed prior to entering detention, despite a number of interactions with the justice system.

When Joseph entered detention NT Legal Aid arranged for him to undergo diagnostic assessment from a service provider in Alice Springs, which is the only provider of assessments in the area. As a result, Joseph was granted access to the NDIS.

Joseph’s diagnostic assessment recommended a number of specialised supports, but these do not exist in Alice Springs. This has caused significant delays in establishing his NDIS plan, as any supports provided to Joseph in detention will need to be delivered by visiting interstate service providers.

In this time, Joseph has been released and subsequently detained again due to re-offending resulting from a lack of necessary supports.

# Models that are working well

In developing a framework for addressing thin market challenges and a roadmap for developing and delivering practical trial projects, we encourage consideration of what is working well.

As we discuss in this part, a key to successful outcomes from our clients has been skilled coordination by someone with knowledge of the system, who is also creating accountability and responsibility to provide services.

Conversely, as the stories throughout this report have identified, a common theme for our clients facing ‘thin markets’ is the lack of systemic coordination i.e. no one agency or works is responsible for the person’s supports and for navigating the system. This is particularly acute for people who face additional barriers to doing that themselves.

Models we see that are working well, which should be continued, invested in and replicated are set out below.

Importantly, something that is not yet evident but is critically overdue is a systemic framework of accountability for guaranteeing people the services they are funded to receive.

# Victorian State-based Intensive Support Team – an expert escalation service

The Intensive Support Team run by Victoria’s Department of Health and Human Services has been largely successful when VLA has escalated clients in acute crisis for response through this model.

**Victorian State-based Intensive Support Team: An expert coordination service**

The DHHS Fact Sheet describes Victoria’s Intensive Support Team in this way:

‘*The Intensive Support Team (IST) is a team within the DHHS Disability and NDIS Branch established to provide time-limited intervention to current Victorian disability clients experiencing significant and critical issues with their transition to the NDIS*’.[[12]](#footnote-12)

It identifies the target group of the IST as ‘*current Victorian disability clients with complex needs or circumstances who are experiencing significant issues in their NDIS transition, where the risk of an adverse outcome for the person is high, and the need for intervention is time critical due to the impact of the issue*’. Specific examples are listed:

* *people who have been unsuccessful in resolving their concerns with the NDIA planning process and the lack of resolution is leading to a (potential) gap/loss of critical services and significant risk to the person (this includes situations where a support coordinator has been unable to resolve the issues)*
* *people who were in receipt of state funded supports that do not align with NDIA support types, requiring negotiation about how their reasonable and necessary disability needs can be met*
* *people use a combination of disability related and mainstream supports and require coordinated planning across mainstream service systems such as health or justice.*

Victoria’s Intensive Support Team’s role has included triage, coordination and problem-solving, most commonly for clients involved in the justice system.

This model adds accountability and whole-of-government (State and NDIA) coordination into the system and enhances the skills of the multiple bodies engaging with the person. Prior to the creation of this team, clients and their lawyers had no idea what to do or where to go to resolve cases of crisis. The clear message from the Victorian government through this process is that there is support for vulnerable people who are reliant on disability support to live their lives.

It is not clear whether this service will continue post-transition. In our view, it should (whether resourced and coordinated at the State or Federal level). We are deeply concerned that should it be removed, we would return to a situation with no ability to bring cases of market failure resulting in crisis and significant human rights breaches to attention and resolution.

Crucially, however, this mechanism continues to be ad hoc, based on case-by-case escalation. We reiterate that a systematised and efficient approach for people with complex needs at the interface NDIS and mainstream systems needs to be put in place and promoted.

# Innovative, skilled support coordinators

Recognising the potential benefits of effective planning for participants with complex support needs, we welcome the commencement of the Complex Support Needs Pathway and look forward to working with the specialised planners and skilled support coordinators and understanding the impact and outcomes of this program.[[13]](#footnote-13)

In our view, for clients with complex needs and behaviours of concern, innovative, skilled support coordinators are an essential part of the NDIS regime. VLA clients have been directly assisted by the capacity of skilled and experienced case managers to problem-solve complex cases and think creatively about supports. Such specialised services are essential to ensure that those who have complex needs and cannot advocate for themselves do not become subject to a second tier NDIS that entrenches disadvantage. For this reason, we would suggest that support coordination should not be seen as merely an initial or introductory requirement for those with complex needs but is recognised as the foundation that keeps other supports in place, either until they are clearly established, or ongoing.

In this context, we are concerned to learn of cases where support coordination is being reduced or removed for clients at plan reviews, including those with complex needs.

1. Names and some identifying details of clients have been changed throughout this submission. [↑](#footnote-ref-1)
2. See Victoria Legal Aid, *Annual Report 2017–18* (available at: https://www.legalaid.vic.gov.au/about-us/our-organisation/annual-report-2017-18).This includes clients seen by a private practitioner duty lawyer. Unique clients are individual clients who accessed one or more of Victoria Legal Aid’s legal services. This does not include people for whom a client-lawyer relationship was not formed, who received telephone, website or in-person information at court or at public counters or participated in community legal education—we do not create an individual client record for these people. Neither does this client count include people assisted by our Independent Mental Health Advocacy service. We note that, because this figure relies on clients disclosing their disability or mental health issue at the time of receiving legal assistance, the actual number of clients experiencing disability or mental health issues is likely to be significantly higher. [↑](#footnote-ref-2)
3. See also Victoria Legal Aid submissions to: the Joint Standing Committee’s *Inquiry into market readiness of the National Disability Insurance Scheme* (March 2018) and *Inquiry into transitional arrangements for the NDIS and into general issues around the implementation and performance of the NDIS* (November 2017); Productivity Commission’s *Inquiry into the National Disability Insurance Scheme Costs* (July 2017) (available at: https://www.legalaid.vic.gov.au/about-us/strategic-advocacy-and-law-reform/access-to-justice-for-people-with-mental-illness-and-disability). [↑](#footnote-ref-3)
4. The Joint Standing Committee’s ‘Market Readiness Report’ recommended that ‘the NDIA publicly release the outcomes of the Maintaining Critical Supports project and its policy on provider of last resort (PLR) arrangements as a matter of urgency’ (recommendation 24) in September 2018. This is the third time that Committee has highlighted that the publication and implementation of a PLR arrangement (or similar framework) is necessary. These remarks have been echoed by the Productivity Commission, the Australian National Audit Office and in the McKinsey & Company Independent Pricing Review. See Joint Standing Committee on the NDIS, *Report on Transition Arrangements for the NDIS* (2018) and *Report on Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition* (2017); Productivity Commission, *National Disability Insurance Scheme – Costs* (2017) 36; Australian National Audit Office, *National Disability Insurance Scheme—Management of the Transition of the Disability Services Market* (2016*–*2017) 27; McKinsey & Company, *Independent Pricing Review*, Final Report (2018) (see especially 59 onwards). [↑](#footnote-ref-4)
5. See, eg, National Disability Services, *NDIS Market Dynamics Study: Victorian NDIS Sector Development Project* (April 2019) 8: ‘People with complex, specialised need or challenging behaviours are at particular risk of missing out on services’. [↑](#footnote-ref-5)
6. Office of the Public Advocate, *The Illusion of ‘Choice and Control’: The difficulties for people with complex and challenging support needs to obtain adequate supports under the NDIS* (2018) 26. [↑](#footnote-ref-6)
7. Emma Younger, ‘Man with intellectual disability released from Melbourne prison after judge 'horrified' by conditions’ (24 November 2017) (available at: <https://www.abc.net.au/news/2017-11-24/judge-releases-man-with-autism-from-melbourne-jail/9186352>); ‘Emergency intervention removes disabled young man from prison’ *7.30* (9 November 2017) (available at: <https://www.abc.net.au/7.30/emergency-intervention-removes-disabled-young-man/9135942>). [↑](#footnote-ref-7)
8. Anonymised name of respite service. [↑](#footnote-ref-8)
9. See, eg, Victorian Ombudsman, *Investigation into the imprisonment of a woman found unfit to stand trial* (October 2018) (available at: https://www.ombudsman.vic.gov.au/News/Media-Releases/imprisonment-of-woman-found-unfit-to-stand-trial). [↑](#footnote-ref-9)
10. Ibid. [↑](#footnote-ref-10)
11. Miki Perkins, 'We are drowning': Sam doesn't have mental illness, yet he's living in a psych ward’ *The Age* (7 March 2019) (available at: https://www.theage.com.au/national/victoria/we-are-drowning-sam-doesn-t-have-mental-illness-yet-he-s-living-in-a-psych-ward-20190306-p5128a.html). [↑](#footnote-ref-11)
12. See Department of Health and Human Services, *DHHS Intensive Support Team: Fact* sheet (May 2019). [↑](#footnote-ref-12)
13. NDIS, ‘Improved NDIS planning for people with complex support needs’ (16 November 2018) (available at: <https://www.ndis.gov.au/news/1002-improved-ndis-planning-people-complex-support-needs>). [↑](#footnote-ref-13)