SUBMISSION TO THE FAIR WORK COMMISSION

Re: Supported Employment Services Award 2010:

Matter Number:- **AM 2014/286** 2 November, 2019

Further to the Directions Notice following the Full Bench Hearing in Sydney on 23/10/2019 - re the above matter- we request the Bench to heed the wishes of our ADE workers – their families and carers – and not to delay the Full Bench decision for AM2014/286 (previously AM2013/30).

This Review of the Award has been the subject of 5 years of conciliation, two weeks of Full Hearings in February, 2018, and has received an interim decision. This has then been challenged by AED Legal and Union representatives (the applicant parties).

Following a further Hearing in November, 2018 the Commission reserved its decision. We now understand that the final decision was to be brought down in coming weeks.

By submission dated 21/10/2019 the Department of Social Services has now requested the Commission further delay their decision until next year – stating they will need nothing less than 12 weeks with a further undetermined time frame to consult with the wider community. They state they need this time to consider the new NDIS pricing framework for supported employment.

The resultant lack of an industrialised wage base determination for our ADE's , the emerging NDIS landscape and the national economic uncertainty with high unemployment and wider global financial insecurity has been detrimental to the sector, the workers, their family carers and the wider business and social community.

In accordance with your Directions as listed 23/10/2019, we provide our submission requesting that the Full Bench Decision – whatever it might be – not be delayed any longer.

We provide the following reasons to endorse the urgency for our workers to have an industrial decision on which their levels of support via the NDIS can be based.

1. No one is more vulnerable, nor have they waited longer or fought harder for wage justice in this matter than those whom we represent. *Justice delayed – is Justice denied* for them. It has been delayed far too long, already.
2. The primary applicant party AED Legal has agitated in correspondence to the Fair Work Commission (dated 18 July, 2019 and August, 2019) that *"the matter is pressing, given*

the time that has elapsed since the last Full Bench Hearing in November, 2018 and the provisional view expressed in a statement released by the review Full Bench in April, 2018". Our workers and their family carers concur with that view. They live with the resultant insecurity of that delay and want it to end. We, their family carers, feel like-wise. We've all had enough. Their jobs count – to them, and the wider community.

3. The Department of Social Services (DSS) cannot claim they are "*not a party to these proceedings",* and then cause greater consternation and anxiety for our disabled ADE workers and their family carers by asking for further delays. No one – not they, not the applicant parties, not any legal agency (AAT, FWC, AIRC, Federal Court, High Court) in the past 16 years can deny that Australian Disability Enterprises (ADE's) have now, and have always had, a duality of focus – those being social and employment (work). The former is the province of the Department of Social Services. The latter is the Industrial Commission. Our communities throughout the length and breadth of our nation support both threads of the ADE community fabric. As the Department of Social Security (DSS) submission states Page 2.11 *"ADE's are typically not-for-profit organisations that provide a wide range of employment opportunities to people with disability, who would not otherwise be able to find work in open employment. ADE's predominantly employ people with disability*" What their submission does not confirm is that the majority of those employees have an intellectual disability, which is, in many cases, a moderate to profound level. It is a matter of fact and legal acknowledgment that our ADE's have a duality of purpose which creates two distinct yet separate arms of the one enterprise.
4. The National Disability Insurance System (NDIS) is an entitlement system – not a welfare system. Many of our members fought for many years for its introduction. The NDIS funding is only for the participants who have been recognised as being eligible for the support assessed. It funds support and cannot be used to pay wages. The NDIS covers many aspects of our disabled worker's lives. Employment is one. That assessed level of funding is incorporated into their personal plans- and reviewed annually. The NDIS legislation specifically states that the NDIS will not act as an interloper with respect to taking over the roles and responsibilities of another system which, in this case, is the Department of Social Services (DSS).

The DSS Submission:

The submission as presented by the DSS at this late stage of 5 years of conciliation and arbitration seeks to further delay the industrial outcome for the thousands of workers dependent on this decision. Despite national recommendations to the contrary (National Family Carers Voice 2004) the DSS has steadfastly refused, over the past 20 years to provide any voice for these workers, their families and carers – let alone one dedicated to their special needs and/or advocacy on their behalf. Our workers were represented by the self-funded Australian Parent Advocacy Voice back in 2003-04 (*The Safety Net Wage Case).* The then Australian Industrial Relations Commission (AIRC) – like the Fair Work Commission now- recognised that the workers should have representation before them on such an important issue. That's the basic human right of all Australian Workers. The DSS have always funded the alternate voices under their National Advocacy Program- i.e. AED Legal, Disabled People's Organisation Australia {(DPO (A)} and their affiliated networks. This combined Advocacy-DSS- Bureaucratic network of ideological law-fare (warfare) is why we are still here, 5 years later, advocating for our disabled worker's right of choice – and an independent wage determination under industrial law – not ideological theory. With consistent and meticulous intransigency, the DSS continues to deny us resources to establish a secretariat to represent people with moderate to profound intellectual disability and complex support needs, in all facets of their life, not just employment. These workers are our disabled family members. They form a large part of the workforce in our ADE's. They will tell you, and have done, in no uncertain terms that - "***MY JOB COUNTS***". Yet, without the assistance of Carers Australia providing basic travel and accommodation expenses, our commitment in presenting their case, the commitment of our family members and the understanding of the Fair Work Commission – these workers would have been totally voiceless. We ask you. They ask you - is that justice?

Now, as we near the end of this 5 year Fair Work Commission industrial journey, the Department wants to delay it. Not surprisingly, based on the history and public record, the alternate voices, despite their earlier agitation for an urgent decision, now support that delay. Wages are a basic commercial cost. Is the delay justified? What are the advantages? What are the disadvantages for the workers and the business services?

Let's evaluate the business case as presented in the DSS submission now before us.

1. It is a basically flawed commercial model. What business model would assess the support levels for workers before any definite projection of the true extent of wage costs – as determined by the independent referee (the FWC). The greatest determinant of expenses for any business – no matter the model – is wages and productivity. Even basic family budgeting must know what the revenue and expenses are before you know what can be afforded.
2. Whilst the average hours worked by employees is standard practice – there seems to be little consideration that those needing the highest levels of support probably work the least hours because of their circumstances and level of disability. What does this do to the modelling?? What does that do to productivity? What does that do to rostering issues for the business, the end product and the most productive outcome for permanent employees working longer hours?
3. Specifically Page 6 of their submission addresses the "*Implications of Changes to Funding*". (Points 47-50). This is the purported reason to further delay the Full Bench Decision. How can their argument for further delay be given any credibility when it is filled with projections that state

    3.1 (Pt 47) – The amount of funding in participant plans ……"***is likely to increase*"**

    3.2 (Pt 48 – *"the increase in funding available for employment supports* ***may be relevant to*** *an ADE's capacity to* ***fund the wages*** *of supported employees "*

    3.3 (Pt 48(a) – *"an increase in funding* **may lead** *to an enhanced service…….thereby resulting in* **higher productivity/output***"*

    3.4 Pt 48 (b) *The increase in funding for supports* ***may mean that ADE's may have the ability to direct more of their revenue to employee wages"***

    3.5 Pt 49 – *ADE's which currently use wage assessment tools other than the MSWS(Modified Supported Wage System) the increase in funding* ***may make it viable to transition to using the MSWS for all their supported employees"***

    3.6 Pt 50 - *It* ***may be appropriate*** *for the Commission to seek further submissions from ADE's (and others) in relation to potential changes to wage assessment arrangements and, in particular,* ***the use of the MSWS as the single wage assessment tool***

Collectively the facts are:-

1. Supports are paid to the worker – not the business. Those supports form the basis of the “choice and control” element of the NDIS – so the employee can take them with him/her should they so choose. The downside of that for business solvency and planning is that – if the job doesn’t suit – they leave and take their support funding with them. Again if the employee doesn’t use it all in one year – it will be reduced in the following one. Where’s the worker’s choice and control in that?

2. How can any business rely on personal support systems for their workers – if the wage component is an un-known? You must know the wage business cost, before you know what support levels are required for the wage recipient where, for whom, and when. That is the most basic element in Grade 1 - Business Principles. An ADE has significant structural and process issues not reflected in the standard private enterprise – open employment - business model.

3. The ADE’s are acknowledged as not-for-profits. They cannot trade if they are insolvent and whilst the business model is valid – it is exceptional in that it is built around the needs of the workers – not vice-versa as with private enterprise. The onus for solvency often falls back onto individuals on the Board of Directors – a typical NFP (Not-for-Profit) model.

4. NDIS support entitlements are based on several concepts – one of which is *“reasonable and necessary supports”.* It must result from the individual’s disability and must provide certain outcomes. As the NDIS system is being implemented this has not remained an objective outcome for some participants and it has become the subject of reviews.

5. How does one measure the “*reasonable adjustment*” necessary for modification to tasks in the ADE, for supports considered necessary when compared to open employment. The test of “*reasonable*” varies with individual interpretation. What is “*”reasonable”* in Melbourne might not be *“reasonable”* in the Hunter, in Whyalla, in Dubbo, in the Alice, in Rockingham, in the Wide Bay, and/or any of the rural, regional or remote areas of our vast country where the tyranny of distance reigns supreme. Existing wage tools have been ruled not fit for purpose. Retro-fitting a model never provides the best outcome. So, let’s get the decision, pick it up and get on with it. Let’s stop trying to fit uneven corners into pigeon holes on the basis of ideology.

6. Point 50 re-iterates a position which the Department has previously repudiated. In a submission to the Fair Work Commission on 16 August, 2017 *(Refer Appendix 1*), the DSS Secretary stated that *“The Department’s preferred position is that the varied SWS is the only wage assessment tool in the SES Award…”* As history confirms all parties to the conciliation and arbitration accepted the inclusion of this *“varied SWS*” tool (later called the Modified Supported Wage System – or MSWS) provided it remained optional (because of projected insolvency issues for some services) – and did not become mandatory. We can understand that the Department is risk-averse post the BSWAT Payment Scheme – but they also know, as do the applicant parties, that the provisional Statement issued by the Full Bench in April, 2018 – after two weeks of Hearings, after visiting several ADE’s , after a mountain of evidence (we alone provided 55 witness statements from our members) found that the existing tools – and that includes the MSWS, the SWS and all the others now in the Award – were not fit for purpose when assessing people with a disability in our ADE’s, and needed to be replaced with a classification system. Now the Department states that increased levels of support for the workers “***may* lead to ……the MSWS being used for all their workers and to it being the single wage assessment tool,** despite the interim conclusion by the FWC (the industrial and independent umpire) that all existing tools – and that includes the MSWS- lacked suitability for our disabled ADE workers. Such a *“may lead to”* outcome would have the Department achieving its preferred wage tool- a

preference which co-incidentally aligns with the goals of the applicant parties – if not the disabled ADE workers, their family carers, Australian communities and businesses.

7. The Department (DSS) has stated that they want the Full Bench Decision delayed so that they (The Department) can ***'engage with the parties***" and then with the wider community. The Department has consistently refused to resource a secretariat for Our Voice Australia – at a minimal cost – compared to the millions that have been allocated to alternate voices – none of which speak for those with moderate to profound intellectual disability – their families and carers. About one quarter (¼) of our membership, and many of the workers, are not computer literate, and electronic contact is not possible. It has to be hard copy or personal discussion.

The Future of Supported Employment

It would seem to us that as the Department (DSS) moves out of and away from supported employment, with the role becoming the responsibility of a different Federal Agency, our workers and their family carers are being carried off on yet another wave of "*transitioning*" to alternate programs.

For our disabled ADE workers that "*transitioning"* might not be "work" in their terms- so every precaution must be taken to ensure our disabled family members are not deprived of an option simply by pricing our ADE's out of existence to suit ideological agendas. Determining the level of funding supports needed for workers with no defined wage base is, primarily, a flawed business exercise.

Yet that seems to be embedded in this DSS submission

The two core facets of our ADE's – social and employment - are not mutually exclusive, with

- the industrial arm of the employment facet resting with the Fair Work Commission, and
- the social arm resting with the Commonwealth Government, and whatever Federal Agency is commissioned to deliver their social policies (of which the Disability Support Pension and now the NDIS) are integral parts.

With a move to an alternate funding model for the ADE's there could be changes necessary to protect the DSP entitlements as well as the notion of supported employment in an ADE – as opposed to open employment.

Removing the option of an ADE – by subtly pricing it out of existence would be a basic breach of human rights – the right of choice. This would be contra to the UN Convention on the Rights of Disabled People. The UNCPRD theme for 2017 was to *"leave no one behind".* The move from the medical model of disability to the social model is and must gain momentum – internationally. Our ADE's will change. That change must come from the bottom up – not the top down, with the business model remaining an option as the users, their family carers and providers weigh up the benefits and changes which the personal NDIS supports of the workers may – or may not – make to the solvency and day-to-day operation of the business enterprise.

What we seem to have is an ambit claim on social policy. The ambit claim on the wage structure is self-evident and has its genesis in a goal of total inclusion in open employment as opposed to supported employment in the ADE model of business. An ADE is not necessarily seen as supported employment by the ideological advocacy networks. Rather it is seen as *"segregated*" employment. So – if you make excessive demands with wages, which result in some compromise, then some of the current workforce will be affected, but some could survive, as the whole concept is transferred inter-agency within the Commonwealth Government. The surviving ADE's die due to attrition and the Department, along with the applicant parties, achieve their goal of having their preferred single wage assessment tool embedded in the Award. That reduces the risk of future (yet again) legal challenges by the advocates, but will also remove jobs for our vulnerable disabled workers because of subsequent insolvency issues.

Throughout all this process – our ADE workers, despite their needs, and their opinion about what constitutes a *'job"* – in their terms – are denied input that aligns with the rights of every Australian worker, whether disabled or able-bodied. Due to DSS intransigency there is no formal, funded advocacy voice for people with moderate to profound intellectual disability. The applicant advocacy parties to the 5 years of this industrial journey are, we are advised by the Department, funded to represent our disabled family members. Those of us who have been passengers on this journey know this is not the fact. We are here because the applicant parties do **NOT** represent our workers – or their family carers on this industrial journey. The applicant parties did not facilitate any site visitations and/or provide any witnesses or witness statements for independent evaluation by any of us throughout the Full Hearings - yet now they support the industrial decision being further delayed.

The Implementation of the NDIS

The NDIS is the largest single social reform in our history. Its' implementation was never going to be without problems. We attach, as Appendix 2, a recent article about the impact of this implementation on those with the highest needs. It is our experience that this is what has happened with the wage issue. This article relates to NSW where we have a large membership base.

We have members with more than one disabled family member. We have at least two families with multiple family members attending an ADE and/or other younger children with disability still at home. Many of these families cannot cope with a Government reliance on electronic medium for contact. The complexities of the journey have become overwhelming. It is the lived experience of many of us that while ever a family carer can "*cope"*, (in Departmental terms), they will be forced to "*cope"*, until the whole family unit is engulfed by a crisis because of the care demands. Some families have been forced to relinquishment, and even I, as the parent of an ADE worker for 25 years – was, at one stage forced to consider that option just to survive and be able to meet the health demands of my husband, my other children and aging parents.

The article included exemplifies the issues between the State v the Federal budgets and departmental guidelines.

It is included to demonstrate that the implementation of the NDIS has been difficult for our family carers – and those for whom they care. The article is indicative of the wider problems with which our workers and their family carers are surrounded.

The insecurity that has engulfed the ADE sector for the past 5 years has exacerbated the stress on the disabled workers, and their families. We are here because they needed to have input. Their voice counts – and so does their job. It is those with the highest needs who have paid the highest price. This is confirmed by the recently released Interim Report of the Royal Commission into Aged Care. Those with the highest needs are the group who will continue to pay the highest price – through all stages of their lives – not just employment.

The Interim Report of the Royal Commission into Aged Care:

We make reference to this Royal Commission Interim Report because it is relevant to the substance of the issue now before us.

The Headlines of the recently published extract of the Interim Report scream "**A shocking tale of neglect".** The extract then commences with the words *"It's not easy growing old".*

It could also have said *"It's not easy having a moderate to profound intellectual disability"* Their family carers would then add – *"which is a **"life-time**" of need and not **"a time-of-life"*** need.

This is not to lessen the shocking tale of neglect for our frail aged, simply to draw on the evidenced vulnerability of those for whom a voice into policy is critical, and for whom a system needs to be holistic and user friendly. The Royal Commission's Report is critical of a system where vulnerable people *"are met with a telephone and internet-based national …*entry system. For our disabled family members this starts – quite often – from birth, through the education system, the health system, specialist accommodation services, specialist education systems, then employment and then into premature ageing. Add in Centrelink, Medicare and it's a never-ending group of silos that encircle the lives of our most vulnerable citizens. We reference our ADE workers as part of that circle. Some of those *"silos"* are the responsibility of different tiers of governance, separate budgets and sometimes different social "policies".

A social policy for our frail aged, like the one for our family members with moderate to profound intellectual disability and complex support needs, which has, as its core concept, a notion that *"most care is "consumer directed" is just not true. Despite appearances, despite rhetoric, there is little choice…." (Extract Royal Commission into Aged Care Quality & Safety- Page 10).* The same could be said of "*consumer choice*" with supported and open employment opportunities.

The support component of the NDIS has now been introduced as the financial and social saviour for workers in our ADE's. Nothing is further from the truth. The core concept of the NDIS is *"choice and control"*. That is quite appropriate for those who can exercise both, who can self-advocate and make informed decisions. Once our disabled family members achieve their chronological age – no matter what their intellectual capacity- they are deemed to have decision-making capacity. Social policy dictates they should be provided with "*support*" to do this. The most obvious choice for that "*support"* is, just like the aged care industry Report attests, those who are their family carers, people who love them, care for them and are able to advocate fearlessly for them.

The Aged Care Report suggests urgent action is needed to *"stop the flow of younger people with disability going into aged care, and expediting the process of getting those younger people who are already in aged care, out."(pg10).* Some of our members have "been there – done that" – but our cries to be heard and helped have fallen on deaf ears – over many, many years.

Reports – ad infinitum (the National Family Carers Voice was but one) – all focus on the one single identified issue and outcome. It is those with the highest needs who miss out – whether that's education, accommodation, employment and eventually aged care, as we all now live longer thanks to modern medical and technology advances.

There is no better example of this tragic fact than the one we face here, with our need to respond to the Directions Hearing imposed by the DSS untimely intervention, after 5 years of them being just an interested "*observer*". Our disabled ADE workers, for decades denied a formal voice, because their "needs" do not fit the ideological model of inclusion, have become victims of social policy which the international evidence – as provided before the FWC Full Hearings - confirms has failed. Advancing their preferred sense of social policy, the rights activists empowered with a funded voice have become applicant parties in industrial action to destroy the model of service which they – not the disabled workers, not the sector, not the business community, not the family carers and not the communities in which they are a vital social thread - have deemed to be inappropriate.

Our ADE workers have not had the advantage of expert jurisprudence and legal representation like that levelled at them by the applicant parties with their legalese on wage justice and legal precedence. As un- resourced family carers we have done our best. This injustice will continue whilst ever the intransigence of DSS continues to deny equitable and dedicated consideration of this group of people through the taxpayer funded National Disability Advocacy Program (NDAP).

Social policy (referred to as the "argy-bargy" of advocacy and activism in earlier – and other – ADE legal proceedings) is not a matter for the Fair Work Commission. The Department (DSS) has now opened that door and seeks an industrial decision based on flawed business projections, which underpin their changes to social policy and the Commonwealth Agency designated to deliver it. The untimely intervention of the DSS, at this stage of these industrial proceedings, combined with the recent release of the Royal Commission's Interim Report into Aged Care, has thrust the dual purpose of our ADE's very much into the spotlight. We have been re-convened before the FWC because of social policy – not industrial policy. Implausible reasons and projections about the impacts of future social policy on our ADE's and supported employment, in general, irrespective of the Federal delivery agency and individualised support funding, should not delay the current industrial decision. NDIS support funding for the individual cannot pay wages and is part of the individual's plan – not the business.

If further adjustment to terminology or legislation is necessary for future funding because of the introduction and implementation of the NDIS, then the Department has known that for years. It is 5 years since the NDIS began its roll-out. As *"observers"* on this current industrial ADE journey the Commonwealth has continued to verbally endorse the ADE model of business, with its social and employment purposes, its community benefits and the sense of self-worth it engenders in its workers. It is, therefore, reasonable to assume that the Department would (and should) always have had a long term vision of what affiliated changes would be needed to existing terminology and legislation, and it has always been abundantly clear that NDIS funding cannot be used for wages, only support for the individual in their employment of choice.

IN CONCLUSION :

Our disabled family members working in our ADE's and their family carers are being asked by the Department to become "*engaged*" with the Department on the issue of how the NDIS pricing might relieve the insecurity of which we have all been victims for the past 5 years. .

The DSS business case (because that's what it is), as provided in the submission to the Fair Work Commission, and the subject of the Directions Notice to which we respond, does not stand up to close analysis. It is flawed.

If the Commission accedes to their request to further delay their industrial decision it will be a case of

………..**Justice Delayed is Justice Denied** ………………….

We submit that the Full Bench Decision should not be delayed on the grounds propounded by the submission from the Department for Social Services.

We request that the Bench hand down their decision as soon as possible

Signed

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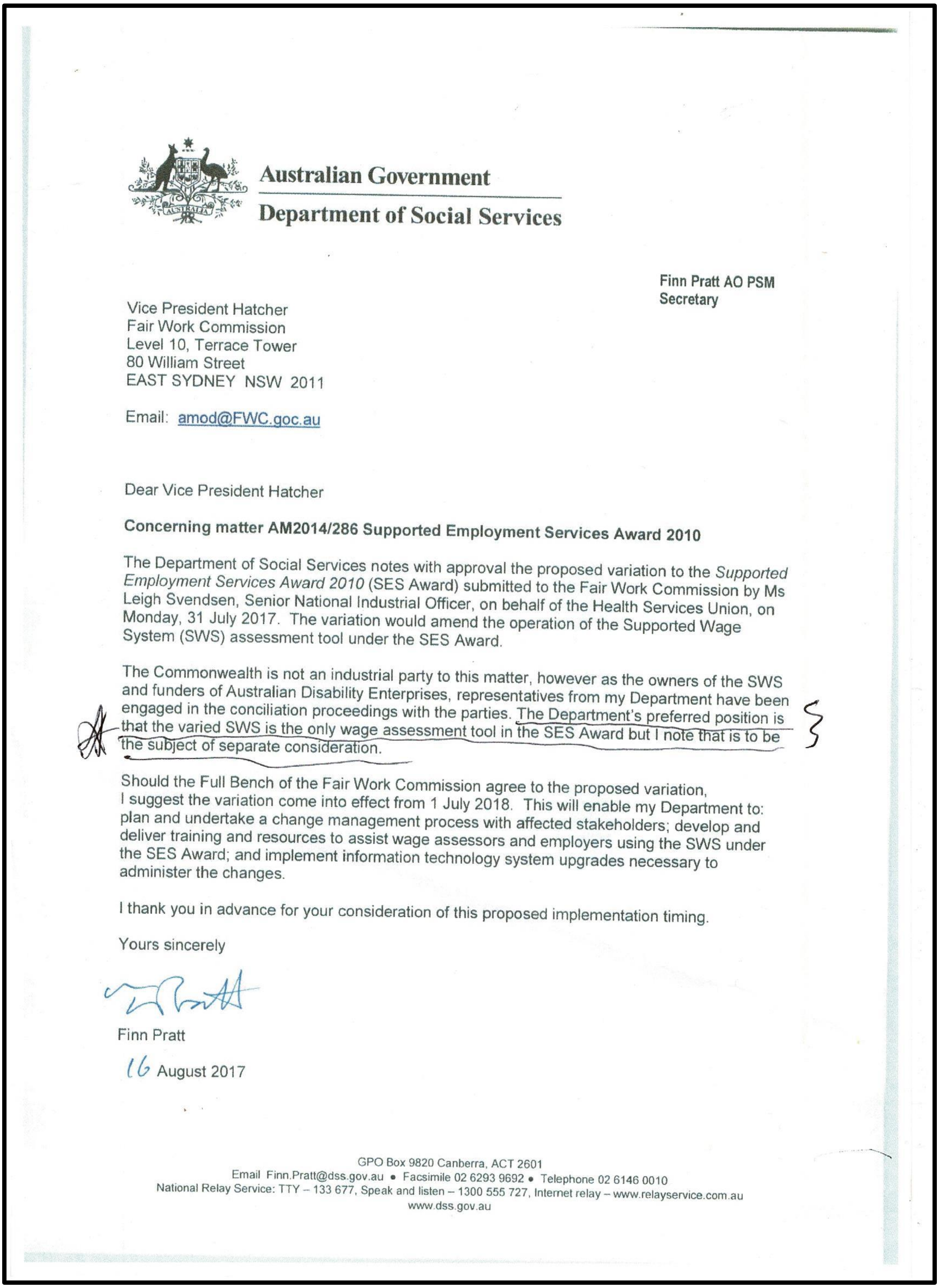
Our Voice Australia



Australian Government
Department of Social Services

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Secretary

Vice President Hatcher
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Dear Vice President Hatcher

Concerning matter AM2014/286 Supported Employment Services Award 2010

The Department of Social Services notes with approval the proposed variation to the *Supported Employment Services Award 2010* (SES Award) submitted to the Fair Work Commission by Ms Leigh Svendsen, Senior National Industrial Officer, on behalf of the Health Services Union, on Monday, 31 July 2017. The variation would amend the operation of the Supported Wage System (SWS) assessment tool under the SES Award.

The Commonwealth is not an industrial party to this matter, however as the owners of the SWS and funders of Australian Disability Enterprises, representatives from my Department have been engaged in the conciliation proceedings with the parties. The Department's preferred position is that the varied SWS is the only wage assessment tool in the SES Award but I note that is to be the subject of separate consideration.

Should the Full Bench of the Fair Work Commission agree to the proposed variation, I suggest the variation come into effect from 1 July 2018. This will enable my Department to: plan and undertake a change management process with affected stakeholders; develop and deliver training and resources to assist wage assessors and employers using the SWS under the SES Award; and implement information technology system upgrades necessary to administer the changes.

I thank you in advance for your consideration of this proposed implementation timing.

Yours sincerely

Finn Pratt

16 August 2017

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THE
SATURDAY PAPER

NEWS

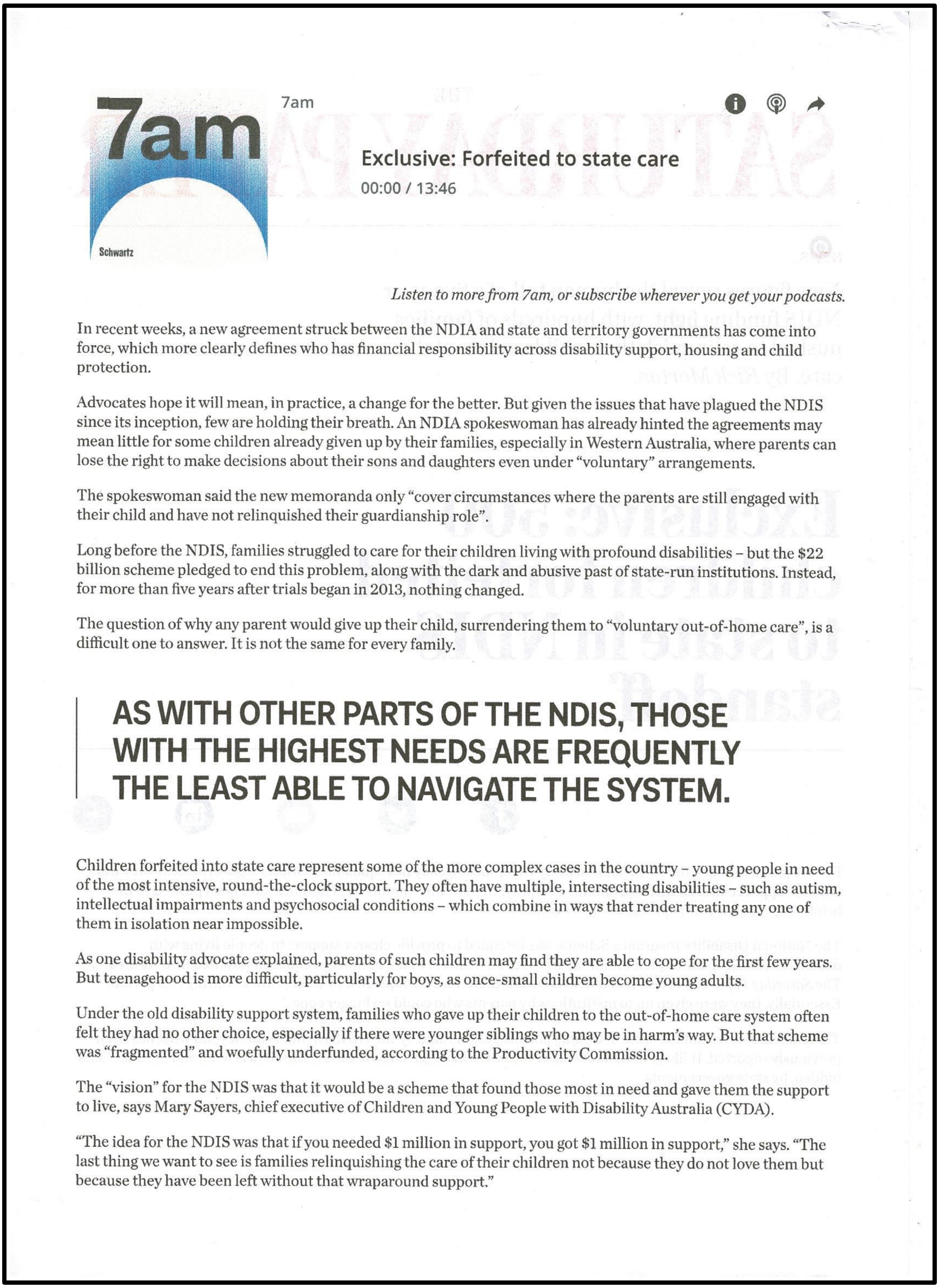
New figures reveal the human toll of a five-year NDIS funding fight, with hundreds of families pushed to relinquish their children into state care. By *Rick Morton*.

Exclusive: 500 children forfeited to state in NDIS standoff

For the past five years, the National Disability Insurance Agency has squabbled with state governments over who pays to support children with a profound disability. In that time, hundreds of families have been pushed to the brink. The care they were promised never came.

The National Disability Insurance Scheme was intended to provide clearer support to people living with disabilities, but its poor implementation has led to an increase in the number of children forfeited into state care. *The Saturday Paper* can reveal that at least 500 children were relinquished by their families during this period. Essentially, they were given up to institutions by parents who could no longer cope.

These figures show that the scale of trauma and distress created by the NDIS rollout is far beyond what has been previously reported. It likely remains a conservative estimate, given how closely this data is held, and in some cases hidden, by state governments.



Exclusive: Forfeited to state care

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In recent weeks, a new agreement struck between the NDIA and state and territory governments has come into force, which more clearly defines who has financial responsibility across disability support, housing and child protection.

Advocates hope it will mean, in practice, a change for the better. But given the issues that have plagued the NDIS since its inception, few are holding their breath. An NDIA spokeswoman has already hinted the agreements may mean little for some children already given up by their families, especially in Western Australia, where parents can lose the right to make decisions about their sons and daughters even under "voluntary" arrangements.

The spokeswoman said the new memoranda only "cover circumstances where the parents are still engaged with their child and have not relinquished their guardianship role".

Long before the NDIS, families struggled to care for their children living with profound disabilities – but the $22 billion scheme pledged to end this problem, along with the dark and abusive past of state-run institutions. Instead, for more than five years after trials began in 2013, nothing changed.

The question of why any parent would give up their child, surrendering them to "voluntary out-of-home care", is a difficult one to answer. It is not the same for every family.

> **AS WITH OTHER PARTS OF THE NDIS, THOSE WITH THE HIGHEST NEEDS ARE FREQUENTLY THE LEAST ABLE TO NAVIGATE THE SYSTEM.**

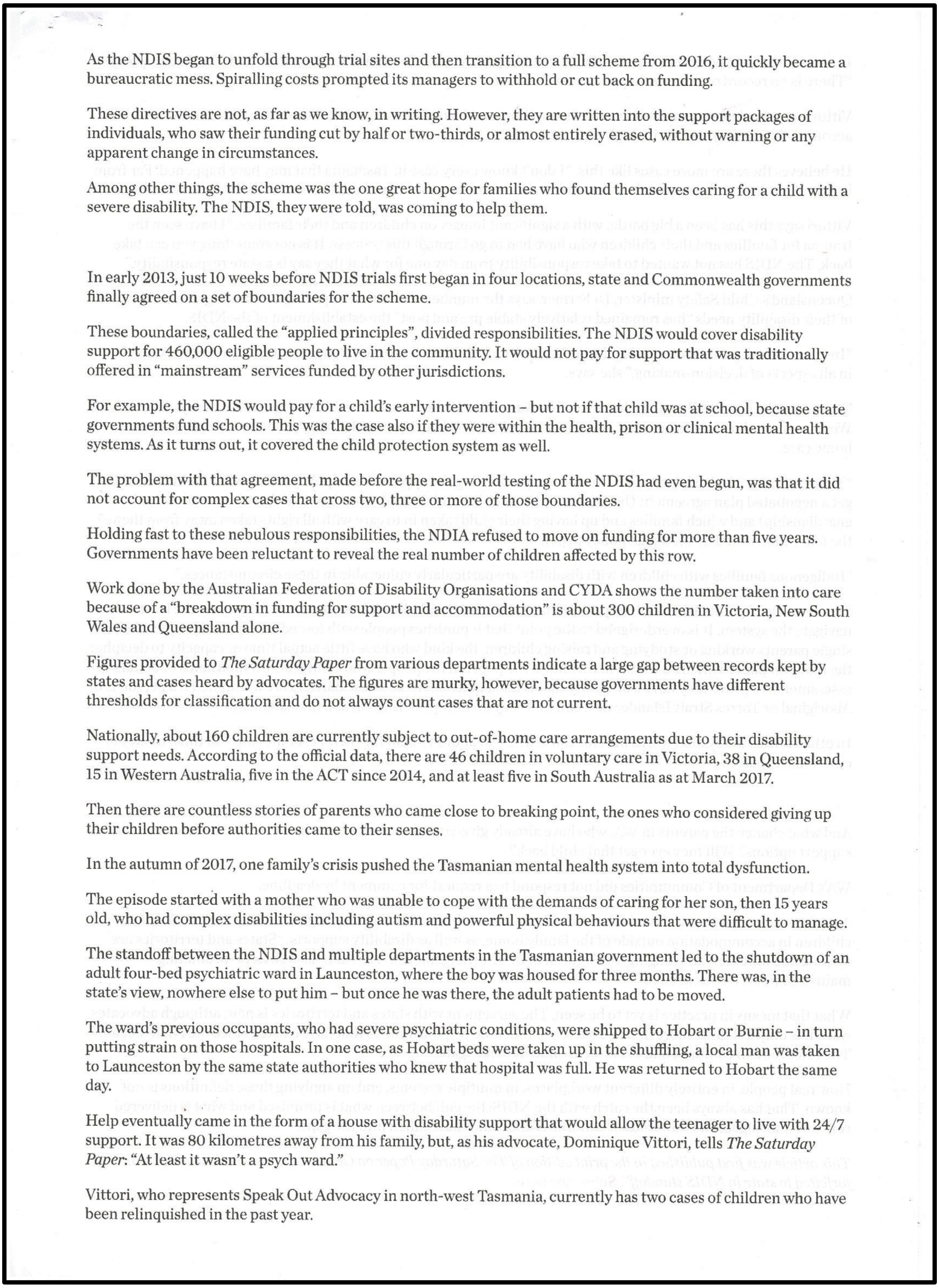
Children forfeited into state care represent some of the more complex cases in the country – young people in need of the most intensive, round-the-clock support. They often have multiple, intersecting disabilities – such as autism, intellectual impairments and psychosocial conditions – which combine in ways that render treating any one of them in isolation near impossible.

As one disability advocate explained, parents of such children may find they are able to cope for the first few years. But teenagehood is more difficult, particularly for boys, as once-small children become young adults.

Under the old disability support system, families who gave up their children to the out-of-home care system often felt they had no other choice, especially if there were younger siblings who may be in harm's way. But that scheme was "fragmented" and woefully underfunded, according to the Productivity Commission.

The "vision" for the NDIS was that it would be a scheme that found those most in need and gave them the support to live, says Mary Sayers, chief executive of Children and Young People with Disability Australia (CYDA).

"The idea for the NDIS was that if you needed $1 million in support, you got $1 million in support," she says. "The last thing we want to see is families relinquishing the care of their children not because they do not love them but because they have been left without that wraparound support."



As the NDIS began to unfold through trial sites and then transition to a full scheme from 2016, it quickly became a bureaucratic mess. Spiralling costs prompted its managers to withhold or cut back on funding.

These directives are not, as far as we know, in writing. However, they are written into the support packages of individuals, who saw their funding cut by half or two-thirds, or almost entirely erased, without warning or any apparent change in circumstances.

Among other things, the scheme was the one great hope for families who found themselves caring for a child with a severe disability. The NDIS, they were told, was coming to help them.

In early 2013, just 10 weeks before NDIS trials first began in four locations, state and Commonwealth governments finally agreed on a set of boundaries for the scheme.

These boundaries, called the "applied principles", divided responsibilities. The NDIS would cover disability support for 460,000 eligible people to live in the community. It would not pay for support that was traditionally offered in "mainstream" services funded by other jurisdictions.

For example, the NDIS would pay for a child's early intervention – but not if that child was at school, because state governments fund schools. This was the case also if they were within the health, prison or clinical mental health systems. As it turns out, it covered the child protection system as well.

The problem with that agreement, made before the real-world testing of the NDIS had even begun, was that it did not account for complex cases that cross two, three or more of those boundaries.

Holding fast to these nebulous responsibilities, the NDIA refused to move on funding for more than five years. Governments have been reluctant to reveal the real number of children affected by this row.

Work done by the Australian Federation of Disability Organisations and CYDA shows the number taken into care because of a "breakdown in funding for support and accommodation" is about 300 children in Victoria, New South Wales and Queensland alone.

Figures provided to *The Saturday Paper* from various departments indicate a large gap between records kept by states and cases heard by advocates. The figures are murky, however, because governments have different thresholds for classification and do not always count cases that are not current.

Nationally, about 160 children are currently subject to out-of-home care arrangements due to their disability support needs. According to the official data, there are 46 children in voluntary care in Victoria, 38 in Queensland, 15 in Western Australia, five in the ACT since 2014, and at least five in South Australia as at March 2017.

Then there are countless stories of parents who came close to breaking point, the ones who considered giving up their children before authorities came to their senses.

In the autumn of 2017, one family's crisis pushed the Tasmanian mental health system into total dysfunction.

The episode started with a mother who was unable to cope with the demands of caring for her son, then 15 years old, who had complex disabilities including autism and powerful physical behaviours that were difficult to manage.

The standoff between the NDIS and multiple departments in the Tasmanian government led to the shutdown of an adult four-bed psychiatric ward in Launceston, where the boy was housed for three months. There was, in the state's view, nowhere else to put him – but once he was there, the adult patients had to be moved.

The ward's previous occupants, who had severe psychiatric conditions, were shipped to Hobart or Burnie – in turn putting strain on those hospitals. In one case, as Hobart beds were taken up in the shuffling, a local man was taken to Launceston by the same state authorities who knew that hospital was full. He was returned to Hobart the same day.

Help eventually came in the form of a house with disability support that would allow the teenager to live with 24/7 support. It was 80 kilometres away from his family, but, as his advocate, Dominique Vittori, tells *The Saturday Paper*: "At least it wasn't a psych ward."

Vittori, who represents Speak Out Advocacy in north-west Tasmania, currently has two cases of children who have been relinquished in the past year.

Despite Vittori's experience, a spokesman for the Department of Communities Tasmania told *The Saturday Paper*: "There is no record of this ever happening in Tasmania."

Vittori says the department "was aware of everything and it is still the case that there is a lack of suitable accommodation for people with high support needs".

He believes there are more cases like this: "I don't know every case in Tasmania that may have happened. Far from it. I think we have only just touched the surface. The state says they have had no cases. Well, I've had two this year."

Vittori says this has been a big battle, with a significant impact on children and their families. "I have seen the trauma for families and their children who have had to go through this process. It is not something you can take back. The NDIS has not wanted to take responsibility from day one for what they say is a state responsibility."

Queensland's Child Safety minister, Di Farmer, says the number of children requiring care arrangements because of their disability needs "has remained relatively stable pre and post" the establishment of the NDIS.

"In Queensland, parents remain legal guardians of their child under these arrangements and are actively involved in all aspects of decision-making," she says.

That is not the case in all regions, however. The Australian Federation of Disability Organisations says that in Western Australia parents have not always remained the legal decision-makers in the context of children in out-of-home care.

"There remains a lack of clarity and transparency regarding the application of policy which affects which families get a negotiated plan agreement (between child protection and disability services and therefore retains legal guardianship) and which families end up having their child taken in to care with all rights taken away from them," the federation noted in an August policy paper.

"Indigenous families with children with disability are particularly vulnerable in these circumstances."

This is a crucial point. As with other parts of the NDIS, those with the highest needs are frequently the least able to navigate the system. It is overdesigned to the point that it punishes people with low education and people who are single parents working or studying and raising children, the kind who have little actual time or capacity to decipher the reams of paperwork. It is a system that hurts the poorest, the people who cannot afford thousands of dollars of assessments to prove they have a disability that is itself quite obvious. These barriers are multiplied if a person is of Aboriginal or Torres Strait Islander descent, or if they do not speak English as a first language.

In other words, the system works best for those who can afford to fight for their best outcome – in time, money or emotional capacity.

And what chance the parents in WA, who have already given up all their rights to their child in the face of miserable support options? Will they ever get that child back?

WA's Department of Communities did not respond to a request for comment by deadline.

A spokeswoman for the NDIA said that from September 1 this year the agency began funding 24/7 staffing for children in accommodation outside of the family home, as well as disability supports. "States and territories are responsible for board and lodging for children in these arrangements," she said, "as well as co-ordinating mainstream services as needed."

What that means in practice is yet to be seen. The agreement with states and territories is new, although advocates warn it is only a slightly more detailed sketch of the same responsibilities that have existed since the NDIS began. The roles remain confused and the system difficult to navigate.

How real people, in entirely different workplaces, in multiple systems, end up applying those definitions is not known. That has always been the catch with the NDIS: the gulf between what is promised and what is delivered remains unbridged, and hundreds of children and families have fallen into the gaps.

This article was first published in the print edition of The Saturday Paper on Oct 12, 2019 as "Exclusive: 500 children forfeited to state in NDIS standoff". Subscribe here.