



# Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

## Submission on laws, policies and practice affecting temporary residents in Australia

August 2021

This submission was prepared by Dr Jan Gothard of Estrin Saul Migration Specialists and is presented under the joint auspices of Down Syndrome Australia and the Welcoming Disability Campaign.

**Patron:** The Governor-General of the Commonwealth of Australia,  
His Excellency General the Honourable David Hurley AC DSC (Retd)

## About Down Syndrome Australia

Down Syndrome Australia was established in 2011 as the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change and provide a national profile and voice for people living with Down syndrome. We work collaboratively with the state and territory Down syndrome associations to achieve our mission.

Our vision is an Australia where people living with Down syndrome are valued, reach their potential and enjoy social and economic inclusion.

Down syndrome is a genetic condition in which the person has an extra copy of some or all of chromosome 21. This additional chromosome results in a number of physical and developmental characteristics and some level of intellectual disability. There are more than 15,000 Australians who have Down syndrome and approximately 1 in every 1,100 babies in Australia are born with Down syndrome.

For more information contact:

Dr Ellen Skladzien, CEO Down Syndrome Australia

Email: [Ellen.skladzien@downsyndrome.org.au](mailto:Ellen.skladzien@downsyndrome.org.au)

Website: [www.downsyndrome.org.au](http://www.downsyndrome.org.au)

## About the Welcoming Disability Campaign

The **Welcoming Disability Campaign** was established in 2020 as a joint initiative between Down Syndrome Australia and Australian Lawyers for Human Rights to seek reform of Australia's migration health laws and their effect on people with disabilities. Spearheaded by representatives from Down Syndrome Australia, Australian Lawyers for Human Rights and migration lawyers, it is focused on reform of discriminatory migration health regulations practices, the exemption of the Migration Act 1958 from the Disability Discrimination Act 1992, and Australia's non-compliance with the UN Convention on the Rights of Persons with Disability as it relates to the international movement of people with disability.

Email: [welcomingdisability@alhr.org.au](mailto:welcomingdisability@alhr.org.au)

Website: [www.welcomingdisability.com](http://www.welcomingdisability.com)

***It breaks my heart to think what we could achieve with that kind of care, [and]... access to proper therapy... made accessible. But it is just beyond our reach as we are not citizens or permanent residents.***

[Shizleen Aishath, citizen of the Maldives, social worker, mother of Kayban, case study 2]

**We are doing our best but it is clear that we haven't been able to give her what she needs to the full extent... Emilia is our pride and joy,... a smart and driven girl who needs help to achieve her full potential. We as parents feel we are failing to give her all that she needs, simply because we cannot afford it. We do our best, but she deserves more and that breaks my heart every day as her mother.**

['R', mother of Emilia, citizen of New Zealand, research scientist, case study 4]

***Once upon a time I could have understood why the government won't support families with children with disabilities that aren't citizens but now that we as New Zealand citizens are having to contribute to the NDIS through our tax yet can't access it - it sucks.***

[Helen Waiomio, New Zealand citizen, grandmother of Mila-Rose, case study 5]

1. Down Syndrome Australia (**DSA**) in conjunction with the Welcoming Disability Campaign (WDC), welcomes the opportunity to provide a submission to the Disability Royal Commission on laws, policies and practice.
2. This submission highlights some of the issues faced by people with disabilities and their families living in Australia as temporary residents as a result of the laws and policies governing access to Commonwealth disability support services, specifically the National Disability Insurance Scheme (**NDIS**).
3. Temporary residents come to Australia primarily as visitors, students and employee-sponsored temporary workers; or are New Zealanders, living in Australia as temporary residents on a special category (subclass 444) visas. Some may be applicants for permanent residence (**PR**).
4. Regardless of which visa they hold, temporary residents are largely ineligible to access many of Australia's social security benefits. This applies to all temporary residents including those on visitor visas, but it has significant negative implications for families with a person, particularly a child, with disability, for those whose stay is longer than a relatively brief 'visit'. For the purpose of this submission, the term 'temporary resident' will not include those in Australia holding visitor visas.

## Case studies

5. This Submission draws on six case studies.

Case study 1: William and Patience MARTIN and daughter Anya [not their real names]

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Case study 2: Shizleen AISHATH, husband Jamshaad and son Kayban

Case study 3: Qasim BUTT, Mehwish Butt and their son Shaffan

Case study 4: 'R', with Ricardo, Emilia and Riaan

Case study 5: Helen WAIOMIO, with daughter Lily and grand-daughter Mila-Rose.

Case study 6: De-Anne FILIPPINI with son James

## Background

6. From a disability perspective, there are many problems associated with the Australian government's migration health requirement as set out in in the *Migration Act 1958* and *Migration Regulations 1994*, and supported by relevant Department of Home Affairs Policy.
7. The Joint Standing Committee Inquiry into Migration published in 2011 as *Enabling Australia – Inquiry into the Migration Treatment of Disability* examined Australia's migration health requirements, and many of the ongoing and unresolved concerns identified in that Inquiry have been raised before the DRC in the University of Sydney's Sydney Centre for International Law, Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, January 2021 [**University of Sydney Submission**], in particular Part II: Migrants, Disability and the Health Rules;<sup>1</sup> and Down Syndrome Australia, Submission to Disability Royal Commission – Rights and Attitudes - Issues Paper August 2020 [**DSA Submission**].<sup>2</sup>
8. The University of Sydney Submission,<sup>3</sup> in Part III: Entitlements after Entry also examines some of the problems faced by temporary residents with disability living in Australia because their visa status makes them ineligible to access some Commonwealth disability supports. In particular, the University of Sydney submission focused on what it refers to as the ten-year rule, which prevents newly permanent residents from accessing the Commonwealth disability support pension until they have been permanently resident in Australian for ten years.<sup>4</sup> The government refers to this waiting period, which differs across different forms of Commonwealth support, as **the newly arrived resident's waiting period (NARWP)**.
9. While the Welcoming Disability Campaign and Down Syndrome Australia have many concerns relating to migration health requirements in general, and with the **NARWP**, this submission does not address those matters in particular.
10. This submission has a different and more specific focus. It addresses the impact on families with a member with disability who are in Australia, especially those with children born here; and a subset of those families on temporary visas, namely New Zealand citizens; of being denied access to NDIS.
11. This submission is supported by six case studies representing these two groups. One submission is anonymous; the others can be contacted on request for further information.

<sup>1</sup> **University of Sydney Submission**, Part II: Migrants, Disability and the Health Rules, pp.35-46

<sup>2</sup> **DSA Submission**, Rights of Migrants with a Disability

<sup>3</sup> University of Sydney Submission, Part III: Entitlements After Entry, pp.46-61

<sup>4</sup> University of Sydney Submission, p.50. The University submission incorrectly states that this is 'particularly harsh on children as it can mean that the disability support pension can be denied them for a large part of their childhood'. The minimum age for eligibility for the DSP is 16.

## What are the issues?

12. The regulations relating to access to Commonwealth social security benefits prescribe certain criteria for eligibility. One relates to residence. Most disability-related social security benefits confine eligibility to
  - Australian citizens;
  - Australian permanent residents, that is, those who hold permanent visas which give them the right to live in Australia permanently; and
  - certain New Zealand citizens, described as ‘protected New Zealand citizens’ or ‘protected SCV holders’: generally, those who took up residence in Australia prior to 26 February 2001 or who meet certain other limited criteria.
13. The University of Sydney submission has addressed the NARWP as it affects permanent residents, since access to benefits for all permanent residents and protected SCV holders is also subject to a waiting period. This issue is not addressed here.
14. Our concern relates to temporary residents. This includes most New Zealand citizens, the majority of whom have arrived since February 2001, are not ‘protected New Zealand citizens’ and who are classed as temporary residents even though their intention is to reside here on a continuing basis (permanent, in fact) and who by law are entitled to do so.
15. Our concern is that these temporary residents are not eligible to access NDIS, and that this has an ongoing permanent negative impact: on the children and families affected, and, ultimately, on Australian society.

## National Disability Insurance Scheme (NDIS)

16. The NDIS, introduced by the Commonwealth government from 2013, was designed to centralise and rationalise the support of individuals with disability across Australia, taking on board the tasks and responsibilities which had previously largely devolved to state governments. It is described as:

Provid[ing] support to eligible people with intellectual, physical, sensory, cognitive and psychosocial disability. Early intervention supports can also be provided for eligible people with disability or children with developmental delay.<sup>5</sup>

17. Among its many aims, the NDIS is designed to provide assistance and support to help people in their daily lives, participate in the community and reach goals. As part of this, it has a strong focus on early intervention, namely:

‘providing support to a person ... as early as possible to reduce the impacts of disability or developmental delay and to build their skills and independence’.<sup>6</sup>

18. It is similarly ‘designed to help people get the support they need so their skills and independence improve over time’.<sup>7</sup>

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<sup>5</sup> See NDIS, <https://www.ndis.gov.au/understanding/what-ndis> accessed 01 05 2021

<sup>6</sup> See NDIS, <https://www.ndis.gov.au/understanding/what-ndis> accessed 01 05 2021

<sup>7</sup> See NDIS, <https://www.ndis.gov.au/understanding/what-ndis> accessed 01 05 2021

19. The General Principles which guide actions under the NDIS Act note, at section 4.4.2:

people with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development (section 4(1));

people with disability should be supported to participate in and contribute to social and economic life to the extent of their ability (section 4(2));

people with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime (section 4(3));

people with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports (section 4(4));

people with disability should be supported to receive reasonable and necessary supports, including early intervention supports (section 4(5));

people with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect and exploitation (section 4(6));

people with disability have the same right as other members of Australian society to pursue any grievance (section 4(7)); and

people with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity (section 4(8)).<sup>8</sup>

## Funding of NDIS

20. The NDIS is funded from money previously spent on disability support by Commonwealth, state and territory governments, from the Medicare levy on taxable income, and from general budget revenue or borrowings.<sup>9</sup> In other words, it is tax-payer funded and anyone who pays tax in Australia contributes towards NDIS.

21. Holders of temporary residence visas – for example, skilled employer-sponsored workers on subclass 482 visas – are required, as a condition of their visa, to hold private health insurance. They are not eligible for Medicare, and hence do not pay the Medicare levy.

<sup>8</sup> See, Overview of the NDIS Operational Guideline – About the NDIS, <https://www.ndis.gov.au/about-us/operational-guidelines/overview-ndis-operational-guideline/overview-ndis-operational-guideline-about-ndis> accessed 01 08 2021

<sup>9</sup> See, Paying for the National Disability Insurance Scheme, [https://www.aph.gov.au/About\\_Parliament/Parliamentary\\_Departments/Parliamentary\\_Library/pubs/Briefing\\_Book45p/NDIS](https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/Briefing_Book45p/NDIS) accessed 01 05 2021

22. However New Zealanders, protected and unprotected alike, are eligible for Medicare under the 1973 Trans-Tasman Agreement, and are therefore required to pay the Medicare levy.
23. Hence, while all income earners and tax payers in Australia contribute indirectly to NDIS, New Zealanders contribute directly via the Medicare levy.

## Eligibility for NDIS

24. The National Disability Insurance Scheme Act 2013 (**NDIS Act**) sets out eligibility for access to NDIS in terms of age, disability and period of residence in Australia. With respect to residence and visa status, section 23 of the NDIS Act states:
  - (1) A person meets the residence requirements if the person:
    - a) resides in Australia; and
    - b) is one of the following:
      - (i) an Australian citizen;
      - (ii) the holder of a permanent visa;
      - (iii) a special category visa holder who is a protected SCV holder; and
    - c) satisfies the other requirements
25. Consequently, temporary visa holders, including non-protected New Zealand citizens, are ineligible for NDIS services.
26. This has significant implications for those temporary visa holders if a family member has a disability.

## Children born in Australia to temporary residents

27. In this Submission, we are not addressing the difficulties facing skilled workers with a family member with a disability trying to enter Australia and keep their family intact. That is a separate issue. Rather, we focus on children of temporary residents who are born here in Australia.
28. Such children and their families have no access to NDIS, and no access to any form of Commonwealth government disability support to assist with accessing essential services such as early intervention.
29. A very high proportion of temporary skilled residents who come to Australia as skilled workers or students do so with the reasonable hope - if their skills are in demand – that they will be able to make Australia a permanent home. There is a legitimate and well-trodden pathway available to permanent residence. The birth of a child with a disability in Australia interrupts that journey. While staying in Australia permanently may still be possible, the path is much more complicated, the emotional and financial cost to the family increases significantly, the outcome is far from secure, and the period of uncertainty waiting for a decision can be extended by years.
30. This has a serious impact on the families-in-waiting but particularly for the children born here with a disability.

31. This section focuses in particular on the situation faced by visa applicants who apply to come to Australia as temporary residents, generally as students or skilled workers, and undergo a health assessment and meet the visa health requirement before entering Australia. We note that the situation for New Zealanders living in Australia as temporary residents is different. While some of the problems they experience are similar, New Zealand citizens follow a different pathway to possible permanent residence and, critically, New Zealand temporary residents do not face the prospect of being required to leave the country because their children - born in Australia or arriving with their families - do not meet the health requirement, even though they too are unable to access NDIS (discussed below).

## Case study 1: William and Patience Martin and daughter Anya [not their real names]

### Background

32. William and Patience came to Australia in 2012 and their daughter Anya was born here later that year and diagnosed with Down syndrome. William had a highly skilled job and was in line for permanent residence, but that otherwise-virtually-automatic pathway was blocked to him as his daughter's disability meant that he had to apply for a waiver of the health requirement because of the costs notionally associated with his daughter's disability.
33. The process of applying for permanent residence took three and a half years, from June 2017 until December 2020. More than two and a half years were spent waiting for the waiver of the health requirement to be assessed, during which time family was in limbo.
34. William and Patience outline the process of waiting in Case study 1. It was 'emotionally draining' and meant their lives were on hold for years while they awaited a decision: unable to commit to buying a home; unsure about having another child because their Australian future was so uncertain; William prevented from considering different professional employment opportunities while their visa was being processed; unable to plan for the future.
35. These issues are a function of the invidious and discriminatory migration health requirement, discussed in other submissions.<sup>10</sup>
36. More particularly, however, and within the scope of this present Submission: from the time of Anya's birth in 2012 until the grant of the permanent visa in 2020, the family could not access any community-funded services for their daughter.
37. They compensated. Patience re-skilled and is now a highly qualified practice leader in the disability sector, a career direction she followed to benefit her daughter, but which clearly benefits the Australian community as well.
38. Other families, however, are less well-placed to do so.
39. William and Patience write:

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<sup>10</sup> **University of Sydney Submission**, Part II: Migrants, Disability and the Health Rules, pp.35-46; **DSA Submission**, Rights of Migrants with a Disability



After Anya was born, we learned everything we could about how to support her development. Patience reskilled and now works full time as a practice leader in the disability sector and has a well-developed understanding of the importance of early intervention to a child's development. She extended her skills and experience working closely with occupational and speech therapist to provide Anya with the skills that enable her to achieve greater outcomes such as fine motor skills, speech, and language skills. We were also able to follow through with the recommendations from the therapists and paediatrician that Anya saw (which we paid for privately).

But there were things that could have helped us a lot in terms of early intervention for Anya.

We unfortunately had to make the tough choice of prioritising services because we had to pay for them by ourselves. Affordability of services was always a factor, so we reluctantly used to limit the visits to some services and plan to do some therapies on our own as per service provider guidelines.

When Anya was referred to a community centre to provide her with Occupational Therapy service in WA [and] it was realised that we were not permanent residents or citizens, the service was stopped, so we ended up using private providers. We were fortunate that we could afford these services because we were both in full time work; however, this could have changed and our ability to provide intervention would have been limited.

40. The family also faced all the expenses which temporary resident families face, in addition to the everyday cost of caring for their children: state school education fees, for example, and private health insurance.

## Case study 2: Shizleen AISHATH, husband Jamshaad and son Kayban

41. Juggling limited finances, and re-skilling to provide allied health and disability support are echoed in case study 2, provided by Shizleen Aishath.

### Background

42. Shizleen and her family are from the Maldives and came to Australia on a Maldives government scholarship so Shizleen could take out social work qualifications, which she did with first class honours.
43. Shizleen was still on a student visa when her son Kayban was born in Bunbury Western Australia in 2016.
44. Kayban acquired a brain injury at birth, complicated by the fact that he was born with haemophilia. The family had no history of this condition. His therapy and care needs are very high and at one stage shortly after his birth, the family was advised by the hospital to switch off his life support, which they did, and agreed to donate his organs. But Kayban survived.
45. His doctors advise that if the family returns to the Maldives, where the support needed for haemophilia and therapy is simply not available, the trajectory of inadequately supported haemophilia means he will almost inevitably die a painful and premature death.

46. Shizleen and her family applied for temporary skilled visas in December 2018, and all but Kayban's visas were granted. His was refused because of the cost of his health care, even though, as a temporary resident, he would not have been not eligible for government health care nor for government-funded therapies or services.
47. There appears little humanity in granting visas to three members of a family - Kayban's parents and two older siblings - but not to baby Kayban.
48. Kayban was not granted a temporary visa for another 15 months, and only then after the family took the matter, at considerable personal expense, to the Administrative Appeals Tribunal (**AAT**).<sup>11</sup>
49. When they apply for permanent visas in 2022, the family will face the same battle and even higher costs to have Kayban considered for a waiver of the health requirement – even though refusal of his visa and leaving Australia for the Maldives is regarded by his medical team as a death sentence.

### Kayban's needs

50. Shizleen writes of Kayban's care needs and how the family meets them, and of the situation she and her family live with as temporary visa holders.<sup>12</sup>

Kayban requires full care 24/7 and he is not able to complete any tasks of daily living independently. His care is provided by me and my husband Jamshaad, who is his full-time carer. [He] does not receive any carer allowance or carer payment because of our visa status as temporary visa holders. He would be eligible to work, but that is impossible given Kayban's care needs.

Kayban wakes up at 5 in the morning. I look after him till about 7 in the morning and then Jamshaad will take over. Kayban is fully peg-fed (he cannot take food by mouth) and has four feeds during the day. Kayban has a nap in the afternoon and sleeps at about 9pm till 1 am. He then would spend his night waking up constantly till 5am which is when he wakes up for the day.

Kayban spends a lot of time doing different exercises to help with his movement and reduce stiffness. Kayban also spends time on the standing frame and cuddling with family plus being in a specially designed chair which gives him postural support while not being close to the floor, and allowing him to engage in conversations with family and try new things for stimulation.

Jamshaad is very hands on with Kayban and Kayban would rarely be not carried by Jamshaad or myself at any given time.

Kayban requires medication for his condition. Kayban has seizure medications twice daily and has appointments at PCH once or twice a month between Rehab, Haemophilia, Ophthalmology and Neurology team.

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<sup>11</sup> The University of Sydney submission, p.44, incorrectly notes that this family applied for Ministerial Intervention and consequently were permitted to stay. The AAT in fact granted Kayban a temporary visa in 2020. However, it is highly likely that the family will in due course need to apply for Ministerial Intervention for permanent residence.

<sup>12</sup> Case study 2 **Shizleen AISHATH, husband Jamshaad and son Kayban**

We work very closely with the Perth Children Hospital Rehabilitation team and utilise my friendships and networks in getting information and expertise in how to best manage Kayban's therapy. This includes Physio, OT and Speech. But Kayban does not engage in ongoing paid therapy as medical and equipment needs have been prioritised. We can no longer afford private therapies. For example, private physio costs \$160 per appointment.

For the last 18 months, the priority has been his surgeries and medical costs including upgrading equipment for example, the cost of a specialised car seat is \$8,025 and a standing frame is \$7,108.00.

Kayban requires a wheelchair for mobilisation – this is the next piece of equipment we need as he has grown out of his current chair - we are looking at \$11,000 to \$15,000 in costs.

Costs for his medical appointments are covered through Medibank private insurance with us paying any gaps. In-hospital services have been covered in full by insurance... Outpatient services are covered to the Medicare rebate rate, and we fund the difference.

So, for example, costs in the case of surgery can look like, an anaesthetist appointment costing up to \$1900, with Medibank [insurance] covering \$500 and us covering \$1300 plus dollars.

The only thing that is funded by the government is his prophylactic injections. The Xynta is covered by the government as it is a requirement for all citizens and visitors alike, to have access to haemophilia prophylaxis when in Australia. His haemophilia is now treated on demand.

Without appropriate care and intervention, Kayban will develop severe complications associated with his conditions including severe contractures, scoliosis, pain, osteoporosis, with a high risk of pathological fractures, hip dislocation, malnutrition, respiratory failure and premature death.

Access to rehabilitation is crucial for Kayban as not having access to this would mean severe pain, possible fractures and other complications which can be avoided with proper care and access to services.

With not even having access to proper therapy and just the medical expertise and care in the home, we have managed to get him to almost five years of age without having to undergo a hip surgery which most kids with his severity get to by the age of three. It breaks my heart to think what we could achieve with that kind of care, [and]... access to proper therapy... made accessible. But it is just beyond our reach as we are not citizens or permanent residents.

51. Like William and Patience, Kayban's needs are met by one family member dedicating their life to the care of their Australian-born child. Patience was able to combine this care and intervention with study and employment, but Kayban's very high physical needs mean Jamshaad is unable to work outside the home, leaving Shizleen alone to provide for their family of three children, as well as meeting Kayban's medical and therapy needs.

### Case study 3: Qasim Butt, Mehwish Butt and their son Shaffan

52. Having a child with a disability impacts on every family member but if no therapies are available to support the child the whole family is impacted, with essential, indeed life-saving purchases and activities necessarily prioritised over the social and financial needs of other children in the family.

## Background

53. Qasim, a citizen of Pakistan, was studying in Australia when his son Shaffan was born in 2014. Shaffan has a rare health condition which could not have been diagnosed, foreseen or treated before birth. Qasim and family applied for a permanent visa in 2016, but it was refused because of Shaffan's medical condition. He applied to the AAT for review but was unsuccessful and is currently awaiting the result of a request for Ministerial Intervention
54. Since his birth, Shaffan has struggled, as have his parents, but he is making progress and now attends Castlereagh School for children with special needs two days a week. However, his medical needs remain profound.
55. Qasim has a master's degree in professional accounting from an Australian university, and two Bachelor's degrees from universities in Pakistan. Qasim's wife Mehwish has a Masters degree in Interior Designing and Fine Arts and a Bachelor of Arts. Neither Qasim nor Mehwish have been able to work in their professions because of Shaffan's 24/7 support requirements.
56. Qasim's family has private health insurance, which covers Shaffan's hospital and medical needs.
57. Having Shaffan living at home involved his parents in intensive training to provide the support he needs. He also remains supported by a coordinated group of medical specialty teams at the Perth Children's Hospital (**PCH**).
58. Shaffan is extremely vulnerable.
59. Despite his parents' excellent care, 24 hours a day, he must have access to emergency medical facilities at all times. His specialists have all confirmed that the facilities he requires for survival are simply not available in Pakistan and have pointed out, bluntly, that to remove Shaffan from Australia to Pakistan will result in his death. International airlines have advised that they would not accept Shaffan as a passenger because the flight would endanger his life.
60. Shaffan is missing out on additional therapies because the family simply cannot afford them. Further, his parents' need to support him 24/7 mean his other siblings, also born in Australia, are unable to live life to the full because their parents' time is necessarily devoted to Shaffan. As a family unit, they need respite and support, and Shaffan needs greater access to therapies than the family is able to provide for him. NDIS would give them some of this.
61. Shaffan and his family live in an Australian limbo. They cannot return to Pakistan because living there in the absence of the medical support would likely result in Shaffan's death if the flight itself did not kill him because of his cervical instability. Regardless – no airline will carry Shaffan so he cannot leave anyway. At the same time they are unable to access the disability supports they need within Australia.
62. Qasim writes of his situation:

We do receive support from the WA state government, which is appreciated in helping to care for and support Shaffan's needs. But we are not eligible for NDIS because of the visa condition.

The visa situation not only impacts Shaffan, but the whole family, from achieving goals that any family would set for themselves to pursue work, study, or spending valuable time with the other children.

As a parents we often feel our lives, and our children's lives, are in limbo without PR. For example, we are not able to apply for jobs to able to apply certain jobs, and we can only access limited socialisation opportunities for ourselves but also for our children, because there is not enough support for Shaffan. It's created a great psychological burden which impacts our and our children's lives.

## Implications and consequences

These three case studies exemplify the issues faced by families with children born in Australia who would be eligible for permanent visas but for the birth in Australia of the child with the disability.

Some families like William, Patience and Anya Martin, will be granted visas by the Department of Home Affairs after a number of years in waiting. Because of the life-threatening nature of both Kayban's and Shaffan's condition, one can only hope that Ministerial Intervention will ultimately grant these families the visas for which they would otherwise be eligible. But while families like these wait for a decision, their children have no access to government-provided services and therapies.

Given the universally acknowledged significance of early intervention in the early development of children with disability, children like Anya, Shaffan and Kayban need both social and physical intervention from birth, regardless of their visa status. Delays in access to early intervention will likely lead to greater dependence and need for supports later in life.

Their families need support too.

The children in these scenarios are fortunate in having parents who have the capacity and commitment to provide as best they can the support and therapies that other families access via NDIS. But they provide this at a cost, financial and social, to themselves and to their other children. Parents taking on a full-time care role, such as Kayban's father Jamshaad, or both Shaffan's parents, have no opportunity to use the qualifications which brought them to Australia in the first place or which would enable them to contribute to Australian industry. Families of children with very high support needs in terms of equipment, physical therapies and 24/7 hands-on care, must prioritise the cost of those supports against the needs of their other family members.

## What if the children are eventually granted visas?

Despite the highest level of commitment from their parents, these children have missed out on the early professional intervention which would have served to enhance their potential for independence and capacity to contribute to Australian society. This is particularly obvious with children like Anya with a disability such as Down syndrome, or with disabilities such as autism spectrum disorder who, with appropriate early therapies, and support will be able to find employment and live independently.

The NDIS and its support for early intervention is an acknowledged investment in the future of Australians with disabilities. These potential permanent residents however are being left behind.

The NDIS principle of -

providing support to a person... as early as possible to reduce the impacts of disability or developmental delay and to build their skills and independence<sup>13</sup>

- has little application when we consider these temporary resident families.

63. Further, if these children and their families are eventually returned to their families' countries of origin, they will be equally disadvantaged, their futures equally diminished by having missed out on early intervention while their families were living here in Australia contributing their skills to the Australian economy and society.

#### Future citizens

64. Finally, given the slow pace at which migration and visa decision are made, a child born in Australia who resides here for ten years, regardless of the citizenship of its parents, is entitled to Australian citizenship after that time. There is every chance that Kayban will still be fighting for a permanent residence visa in 2026 if, as is likely, he has to run the gamut of

- applying for a permanent visa in 2022;
- applying for a waiver of the health requirement;
- being refused because his costs are too great;
- applying for AAT review;
- being refused because his costs are too great; then finally
- applying for Ministerial Intervention

65. When Kayban becomes an Australian citizen at that point in 2026, he will finally be eligible for government support and therapies. He, his family and Australian society would be enriched by giving him access now.

66. The practice of denying families access to services which could change their lives and produce better-supported Australian citizens and permanent residents at the end of the day, seems a pointless and punitive one. It is detrimental to the well-being of children born in Australia, their siblings and parents, and is ultimately detrimental to Australian society. It will inevitably lead to greater costs to the Australian economy due to children missing out on the opportunity for early intervention and the associated long-term benefits.

67. It is also a breach of the UN Convention on the Rights of the Child.

#### New Zealand citizens

68. Many of the points made above relating to children of temporary visa holders born in Australia apply equally to New Zealand citizen children born here in Australia. However, their situation differs in important ways, whether they are born here or enter Australia with their parents.

69. When New Zealand citizens enter Australia, they are granted a special category or subclass 44 4 visa (SCV) and are classed as temporary residents. Those who arrived before 26 February 2001 are described

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<sup>13</sup> See NDIS, <https://www.ndis.gov.au/understanding/what-ndis> accessed 01 05 2021

as protected NZ citizens and are not included in the analysis which follows. As outlined above, New Zealand citizens **who arrived in Australia since 26 February 2001 on SCVs** are considered 'non-protected SCV holders'.

70. While they can freely access some of the community benefits otherwise restricted to Australian citizens and permanent residents, such as Medicare and state education, they have restricted eligibility to social security benefits.
71. This is particularly galling to many New Zealand citizens for two reasons. Firstly, there is limited reciprocity between Australia and New Zealand, with Australian citizens eligible for more social services in NZ than vice versa; and secondly, New Zealanders living in Australia as noted above, are ineligible for NDIS even though they are required to pay the full Medicare levy which is used directly to part-fund NDIS.
72. The case studies which follow demonstrate that New Zealanders living in Australia with a child with a disability face many of the same problems faced by citizens of countries other than New Zealand in Australia on temporary visas.
73. However, the case studies above all focus on applicants for permanent visas who **applied** to enter Australia, met the eligibility requirements and were granted temporary visas. Eligibility includes meeting the health requirement, which stipulates that a visa applicant's medical and community costs must not exceed a certain threshold over the period of their temporary visa. They then applied for a permanent visa after arrival
74. New Zealanders are entitled under present migration regulations to enter Australia **without** the need to apply for a temporary residence visa, and to remain in Australia indefinitely. The SCV is granted to New Zealand citizens virtually automatically on arrival. The consequence of this is that a person with a disability, who holds New Zealand citizenship can enter Australia freely without the need to meet that part of the health requirement pertaining to cost to the community to which all other visa applicants are subject.
75. There is no migration-related restriction on a New Zealand citizen with a disability entering Australia and remaining indefinitely.
76. This can have unforeseen consequences when a child with a disability is born in Australia to a New Zealand family. All the issues outlined above relating to inability to access NDIS are identical for New Zealand families after a child with a disability is born here.

#### Case study 4: 'R', with Ricardo, Emilia and Riaan

77. 'R' is a New Zealand citizen, who came to Australia to undertake her PhD. She met and married her husband Ricardo, a Colombian, who was completing his masters in IT here. Their daughter Emilia was born in Australia in 2019. Emilia has Down syndrome.
78. 'R' writes:

We had Emilia in 2019 when I was 30 and were given a post-birth diagnosis that she had Down syndrome when she was five days old. Prior to this, we had not been in a rush to apply for permanent residence [PR] as NZ citizens seemingly get access to most social benefits. We



were unaware of NDIS, and completely unaware that we would need it for our child and also that we would be absolutely ineligible for it as NZ citizens.

So, we have paid out of pocket for every therapy, every developmental toy, etc. As a result, it has been cost-limiting for us.

I am a research scientist and was working at the Children's Cancer Institute as a post-doctoral fellow. Unfortunately, due to Emilia's poor immune system as a baby, she couldn't handle day care five days a week for me to be able to successfully return to work in 2020 after my maternity leave. My job was very demanding and part time was not an option. We also have no family in Australia. So, I had to prioritise her health and quit.

It was an easy decision for me to put her first, but my ambitious career as a cancer researcher has had to take a backseat. So, we found ourselves down to one salary, no NDIS support, and having to pay for any therapies she may need.

We are doing our best but it is clear that we haven't been able to give her what she needs to the full extent. She is still struggling to walk or talk at two. But she is so incredibly determined and smart, that she is well aware that she is behind her peers especially in her gross motor skills.

We have considered returning to NZ but there is literally no career progression for us there and we have worked very hard, are ambitious, and capable, and also contribute a lot to Australian society. I just recently published my research on treating neuroblastoma [cancerous tumour] in children. We don't want to have to leave solely because the NDIS doesn't give us the support we need to continue to thrive and contribute.

Emilia is our pride and joy and luckily, is medically uncomplex. But she is a smart and driven girl who needs help to achieve her full potential. We as parents feel we are failing to give her all that she needs, simply because we cannot afford it. We do our best, but she deserves more and that breaks my heart every day as her mother.

79. 'R' also notes that simply applying for permanent residence in order to access NDIS is not straightforward. Her qualifications make her eligible to apply for a skilled employment visa but to access a health waiver, she has to have earned over a certain threshold of income in the past few years, which has been impossible for her as she has been caring for Emilia.

Lack of NDIS support is having a huge impact on our lives. To address this, we met with a few immigration lawyers to see if we can apply for a PR. Given that I have a doctorate from the Australian National University and my husband has a very good job working for IBM for nearly 10 years, and me being an NZ citizen, we should have been an easy yes for permanent residence (PR). However due to Emilia's disability we were informed that pursuing this pathway would be very expensive and ultimately futile. Given that we are on one income currently to support our family, and that we also now have a 6-month-old son, and that we pay for whatever therapies and specialists Emilia needs, we can't really afford to fork out so much for a PR that will most likely be rejected. So, we are in a difficult situation.

80. If 'R' and her family can hold out till Emilia is ten years old, Emilia will be eligible for Australian citizenship and therefore supports under NDIS. But in the meantime, she is missing out on essential early intervention and her future is being jeopardised.
81. Other New Zealanders have also considered applying for PR but for New Zealanders to obtain PR usually means they have to have earned income to a certain level over a number of years, or to have job skills which are in particular demand and an employer who will sponsor them (at a cost) for a temporary then a permanent visa. For many families, this is it simply not an option.

## Case study 5 Helen Waiomio, with daughter Lily and grand-daughter Mila-Rose

82. The break-up of families can be a consequence of restricted access to disability support, as Helen Waiomio relates, telling the story of her daughter Lily.

My name is Helen Waiomio, and my daughter Lily has asked me to tell you her story.

We moved to Brisbane from New Zealand in 2008 when Lily was 12 years old. Lily went back to New Zealand when she was 20, met her partner and had Mila-Rose at the age of 21. They found out at Lily's twelve-week scan that Mila had Down syndrome. After the initial shock we all excitedly awaited her birth. We considered bringing Lily back here at the time, but she was under numerous specialists so thought it best to deliver in NZ.

Mila was born on 27th November 2019.

Lily was very homesick, and life wasn't ideal for them in NZ so they moved back to Brisbane when Mila was about 4 months old. They stayed here for approximately one year but could see that life was going to be difficult for Mila's development as they weren't going to be able to access any help for her without considerable cost. Even though at this young age her care was manageable, and we could afford it, the decision was made for them to go back to NZ as going forward she would need access to more services. It was a very hard goodbye with Lily in floods of tears at the airport not wanting to return to NZ.

Mila is now three years old, and Lily has a son who is nearly one. Lily has suffered from severe postnatal depression and continues to struggle with the separation from all of her immediate family. Covid hasn't helped.

How wonderful it would be if Mila had been able to access NDIS! Once upon a time I could have understood why the government won't support families with children with disabilities that aren't citizens but now that we as New Zealand citizens are having to contribute to the NDIS through our tax yet can't access it - it sucks. There are hundreds of thousands of Kiwis working and paying into this scheme. Surely this would more than cover those with disabilities!

Lily is eligible for a Special Category Visa, subclass 444, like most New Zealanders. As things stand, she can return to Australia with her children, but she and they will never be eligible for permanent residency in Australia.

83. Like Helen's, other New Zealand families also face the prospect of breaking up and repatriating to give their children access to the service they need – but this can also be difficult and in some cases impossible.

### Case study 6 De-Anne Filippini with son James

84. De-Anne Filippini knows that she needs to return to New Zealand to give her son James access to the services and therapies he needs but is prevented from doing so by family considerations. Like Helena Waiomio in case study 5, De-Anne's family's roots go deep into the Australian community. All her relatives and extended family live here; her children have grown up here, and James' siblings not only do not want to leave Australia but, for custody reasons, they cannot. Further, her elderly father here in Australia also needs her support.

De-Anne and her then husband moved to Australia from New Zealand seven years ago, in 2014, when her three children were very young. All her ex-husband's immediate family live here and he was transferred here for work. One of her sons, James (now 12), born in 2008, has Down syndrome. They were always aware that James's diagnosis of Down syndrome would make applying for permanent residency difficult; but with the rollout of the NDIS in recent years, they now feel completely excluded from accessing any formal funded supports for his care.

De-Anne reports the family consider themselves 'Aussies' so would prefer not to move back to New Zealand anyway. Her other children were born in 2009 and 2011, have lived most of their lives in Australia, and have no relatives in New Zealand. De-Anne is also now the carer for her elderly father, living here in Australia, whose health is deteriorating. De-Anne's mother lives in Bundaberg, and her father lives with De-Anne and her children. De-Anne's extended family is all in Europe.

James's complex presentation and onset of puberty has led to some challenging behavioural situations for De-Anne to manage on her own. De-Anne, who works in the disability sector, has to work in order to support the family and is ineligible for a Carer Payment. She can, however, only work during school hours, as there is no funded after school care or respite that she can access for James's care, and it is unsafe to leave him alone with his grandfather anymore.

De-Anne feels strongly that denying a child with a disability access to early intervention is a fundamental breach of human rights.

85. In her work, De-Anne has come across many families impacted by the residency barriers. De-Anne is part of several Kiwi groups and would be happy to talk further about the problems she and others like her face because of inability to access support for children with disabilities.
86. Emilia and other New Zealand children born here will be able to become citizens. Those not born here do not have that option. James will not become eligible for Australian citizenship after ten years residence because he was born in New Zealand.

## Recommendations

87. Discrimination against children with a disability in terms of not permitting them access to essential therapies and early intervention, is in violation of the UN Convention on the Rights of the Child.
88. Denying children appropriate and supported access to early intervention and essential therapies reduces their capacity for future independence and their ability to maximise their potential. Such a practice is to the detriment of the individual, to their families and ultimately to the society in which those children grow up, whether that be Australia or any other country.
89. Down Syndrome Australia and the Welcoming Disability Campaign **recommend**:
  1. the provisions in the NDIS Act which prevent temporary residents including New Zealand citizens from accessing NDIS support should be reviewed and changed; and
  2. all children in Australia living with disability should be supported to the utmost, including being given access to early intervention and ongoing therapies, regardless of their visa status.