Submission to Joint Standing Committee on the National Disability Insurance Scheme

Dr Stevie Lang Howson

1. My name is Stevie Lang Howson and I am 34 years old. I have a 9 year old son and live in Armidale in rural, north-western NSW.

2. I am Autistic. I was diagnosed with Autism in 2019 as an adult. I did not seek NDIS support in 2019. I did not think I needed it. I believed NDIS support should be reserved for the people who need it the most.

3. When I was a child there were issues that should have received attention. For example, I could not jump. The way I ran attracted attention and teasing from other children. I did not smile as a small child, I had another expression I would make with one eye closed. I was very uncoordinated.

4. My parents did not understand that this might have signified an issue that needed support. They accepted me for who I was, but didn't seek medical help for me.

5. Despite the increased effort it took me, I have been committed to exercise and a healthy diet since I was 14 years old. I believe this allowed me to delay the current impacts of my physical disability.

6. After I turned 30, I experienced progressive issues with pain, fatigue, balance and mobility. I sought medical advice and was diagnosed with Ehlers Danlos Syndrome (hypermobile type). This is a genetic condition affecting the connective tissue. Connective tissue is found throughout the body including in the joints and muscles.

7. Ehlers Danlos Syndrome (hypermobile type) affects more women than men.[1] The condition is considered under-researched and under-recognised.[2] Some people are not severely affected by it. Others are. They don't yet understand why this is exactly. I am severely affected.

8. More people are realising they have issues associated with hypermobility. The relationship between hypermobility which can be a normal variation and hypermobile Ehlers Danlos Syndrome is not entirely clear.[3] However, because of increased awareness about hypermobility, some people now think EDS is a 'trendy' diagnosis and don't take it seriously.

9. Something being considered 'trendy' and having a wide range of presentations from relatively mild to severe does not mean that people with severe presentations who are disabled by a condition do not need help. Many conditions, including well known

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[1] Demmler, Joanne C., et al. "Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK: a national electronic cohort study and case–control comparison." *BMJ open* 9.11 (2019): e031365.

[2] See above.

[3] Wang, Tina J., et al. "Fascial Pathophysiology in Hypermobility Spectrum Disorders and Hypermobile Ehlers–Danlos Syndrome: A Review of Emerging Evidence." *International Journal of Molecular Sciences* 26.12 (2025): 5587.

disabling conditions like cerebral palsy range from mild and invisible to severe and noticeable impacts depending on the individual.

10. Before I was diagnosed, when the challenges I was facing were in their earlier stages, I purchased a property with a partner in 2021.

11. Due to my increasing physical issues, I was not able to get around our property easily.

12. I was in a lot of pain. I was spending a lot of time in bed. I was not able to be independent, for example, I couldn't go to the shops or cook food.

13. I was still working at a desk job, but it was really hard to have the energy to anything else.

14. I had to stop living on the property due to my mobility challenges. I rented a house in town that was easier to get around. This caused financial strain for me.

15. I applied to the NDIS in September 2023 so that I could get the help I needed to live alone, without a partner.

16. I had just gotten my first wheelchair because I could not remain standing or walking long enough to get my child ready for school or make his lunch in the morning. I bought it second hand, with the guidance of an occupational therapist.

17. When I applied to the NDIS, I was still working four days per week. I was using a wheelchair. I had paid for occupational therapy and physiotherapy privately. I had been to see a range of specialists and doctors. They told me that I would need ongoing support and access to equipment, and in particular, physiotherapy.

18. When I applied to the NDIS I wanted help to get a wheelchair that was fitted for my body and suitable for my condition to allow me to be more independent.

19. I needed enough support worker help to ensure that I could manage my responsibilities as a parent and I also wanted help to move into a home that was wheelchair accessible.

20. I needed some psychology support to manage the impact of my Autism on my relationships and help me develop more insight to have better friendships and be a better parent. I also needed psychology support to deal with the shame and distress I was experiencing about my physical disability.

21. I also needed physiotherapy. This was very important as my mobility was getting progressively worse. Physiotherapy is a key tool for managing Ehlers Danlos Syndrome.

22. I thought that the NDIS might offer me 'early intervention' supports to get me back on my feet, with the equipment and support I needed to stabilise my disability and be independent.

23. In November 2023 I had a planning meeting with two representatives of UnitingCare, who are the ‘Local Area Coordinator’ in Armidale.

24. At the planning meeting the UnitingCare staff were very kind. We developed a plan that included most of what I needed. I felt confident and happy that things were going to be worked out and my life could get back on track.

25. However, after the planning meeting, one of the staff from UnitingCare called me. She said that the NDIA had told her that I could not have the supports that we had discussed.

26. She said that I was only on the NDIS for Autism and that if I wanted support for my physical disability, for example, physiotherapy or assistance accessing a wheelchair, I would need to apply to the NDIS again. I asked how could I apply to the NDIS again, as I am already a participant, she said she didn’t know. She also seemed confused and distressed by what had happened.

27. I did get an NDIS plan, however it looked like it had been written for someone else, not me. I received the following funding that I did not request, or need. This included:

    - Speech therapy $3879.80
    - Behaviour support plan and training $15,240.51
    - Occupational Therapy $5819.70 – this was for a functional capacity assessment. I had already paid for a functional capacity assessment less than six months prior.

28. I suspect this plan was generated through automation. It was not relevant to me or my life circumstances.

29. The funding for a behaviour support plan was particularly distressing to me. Behaviour support plans manage behaviours of concern and the use of restrictive practices. I was an adult without behaviours of concern, parenting and working in a mainstream job. When I went to see a behaviour support practitioner, she said: “Despite a thorough assessment, no restrictive practices were found to be, or have been, in use, and no Behaviours of Concern were identified… Stevie’s dignity and quality of life are not impacted by his behaviour, but rather by deficiencies in disability supports, particularly around mobility challenges.’

30. I later found out the cost of the behaviour support plan would have covered an appropriate wheelchair.

31. It came to my attention that this issue arose because the NDIA had listed my ‘primary disability’ as Autism. In their view, this meant that I could not be supported for Ehlers Danlos Syndrome, despite it being a more significant cause of disability for me at the time.

32. This Joint Standing Committee has previously stated that: ‘The NDIA's distinction between 'primary disability' and 'secondary disability' has no basis in its governing legislation or the reality of participants' lives’ and that ‘it can result in participants

being denied supports for impairments that the agency determines are not related to their 'primary disability'.'[4]

33. This Joint Standing Committee has also stated: 'The distinction between 'primary disability' and 'secondary disability' would therefore seem to raise the prospect that an applicant might be excluded from the scheme, or a participant might be denied reasonable and necessary supports, where particular impairments, or the totality of their impairments, could not be readily attributed to their 'primary disability'.'[5]

34. This committee has recommended 'that the National Disability Insurance Agency assess people according to the totality of their disabilities and no longer require participants to nominate a 'primary disability' and 'secondary disability'.'[6]

35. This Committee has described the NDIA's distinction between primary and secondary disabilities as an 'administrative convenience' with profound negative impacts for participants.[7]

36. The law was later amended to support the NDIS' distinction between eligible and ineligible impairments.[8] But, at the time, this was not the law. The NDIA should have considered the combined impact of my disability as recommended by this committee and as provided for in their governing legislation and the legal precedent at the time. This Committee has previously stated: 'Legal precedents confirm that there is no legislative basis for distinguishing between 'primary disability' and 'secondary disability'. It would, therefore, appear to be an artificial distinction that the NDIA has introduced and imposed.'[9]

37. I did a participant information request and found out that Ehlers Danlos Syndrome was listed on my file, but there was an end-date applied to the listing. I don't know how a disability can have an end-date. No one could explain why this had happened. I asked a lot of different people in the NDIA.

38. I did an internal review (appeal to another staff member in the NDIA) of my plan. They affirmed the decision to give me behaviour support and no assistance with my physical disability.

39. I applied to the Administrative Appeals Tribunal (now Administrative Review Tribunal) in March 2024.

40. The early intervention team who review external reviews told me that the decision to give me behaviour support was wrong. I later found out through an FOI request that this early intervention team member had suggested resolving my matter in a way that would have been satisfactory to me at the time, avoiding the need for an appeal at all.

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[4] Joint Standing Committee on the NDIS, *The Culture and Capacity of the NDIA,* (Report) https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/CapabilityandCulture/Report, 2.29.

[5] As above, 2.35.

[6] As above, 6.11.

[7] As above, heading section 2.30.

[8] *National Disability Insurance Scheme Act 2013* (Cth) s 34(1)(aa).

[9] Joint Standing Committee on the NDIS, *The Culture and Capacity of the NDIA,* (Report) https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/CapabilityandCulture/Report, 2.30.

41. However, her advice was overruled by the 'TAPIB' Technical Branch at the NDIA. They didn't give many reasons why, stating only that Ehlers Danlos Syndrome was complex.

42. The NDIA engaged lawyers to represent them. I was very fortunate that Legal Aid ACT took on my case. This meant that I also had a lawyer. This is unusual and I was very lucky that my matter was listed in the ACT and was able to access this support as most people are unable to access Legal Aid for NDIS matters.

43. Throughout the appeal, the NDIA lawyers said that I could not receive support for 'impairments associated with EDS.'

44. They said that these impairments were not permanent, and that they did not cause significantly reduced functional capacity but they did not explain why they thought this. It is very hard to become a wheelchair user in your thirties and be told this is not a significant impact by the NDIA.

45. Changes to the NDIS were announced around this time. At first I was excited, because the then-Minister Bill Shorten said that this would end the reliance on primary and secondary disability, as the NDIS review recommended and as this committee has recommended.[10]

46. However, once the new legislation was introduced to parliament it became clear that it legislated an idea of eligible and ineligible impairments.[11]

47. In the context of the new legislation, impairments are supposed to be broad categories, things like 'physical' or 'intellectual.' The new legislation said we were supposed to get a clear 'Notice of Impairments' that would allow us to review the impairments we have listed with the NDIA.

48. However, the NDIA did not give me a notice of impairment. Throughout my appeal they proceeded as though I had an eligible *diagnosis* – Autism, and an ineligible *diagnosis* – Ehlers Danlos Syndrome.

49. In my experience, the NDIA has used the terms impairment, diagnosis and disability interchangeably. This is confusing. It also does not seem to comply with the NDIA's governing legislation. It reinforces a medical concept of disability by equating a disability with a diagnosis. It orients the NDIS towards fixing or compensating for diagnoses, rather than including people.

50. In July 2024, I was able to access a better wheelchair through the JobAccess program. I was assessed by a JobAccess OT, who prescribed me a custom manual wheelchair designed to be easy to travel with. My job at the time required some travel. As I was only assessed by the OT in my workplace, the wheelchair I was prescribed does not meet the needs I have living in a rural area.

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[10] Minister Shorten's Second Reading Speech stated 'we won't distinguish between primary and secondary disabilities any longer.' https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22chamber%2Fhansardr%2F27626%2F0059%22

[11] *National Disability Insurance Scheme Act 2013* (Cth) s 34(1)(aa).

51. Using a wheelchair that is designed for travel and city life in a rural area has caused injury to my hands and shoulders. I also still can't go on grass to a park with my son or take my dog for a walk. It is the wheelchair I needed for my job, not the wheelchair I needed to be independent across my life.

52. In August 2024, the NDIA asked me to do a functional capacity assessment with an OT they had chosen. They thought this would get better information. The OT came to my house. This was very stressful to me. My lawyer assessed this report as demonstrating that I had significantly reduced functional capacity in the domain of mobility. The assessor said I needed physiotherapy and a review of my mobility aids as she had concerns that the wheelchair I was using would place too much strain on my shoulders and upper limbs. This concern has been borne out, and I have experienced deteriorating hand function over the course of the appeal. Despite commissioning this report, the NDIA did not fund physiotherapy for me until almost a year later. The NDIA commissioned this report, but did not end up using it much as it identified that I have a lot of physical challenges and didn't talk much about my Autism. The NDIA held the position that I could not receive support for my physical impairment.

53. I asked my own professionals to do more assessments. During 2023 and 2024 I had four functional capacity assessments. They all said relatively similar things. Being assessed this many times was really hard for me.

54. In November 2024, I had a conciliation with the NDIA in the Administrative Review Tribunal. The NDIA case manager and lawyer seemed confused and apologetic. They thought maybe a mistake had been made. They said they needed to get technical advice about adding Ehlers Danlos Syndrome to my participant file.

55. They got the technical advice from the TAPIB. The lawyers told me Ehlers Danlos Syndrome could not be added to my file. They did not explain why, just saying that it did not align with the access criteria.

56. I later accessed this TAPIB advice through freedom of information request. It was a very distressing document to read.

57. They made a lot of mistakes in their 'advice' because they never spoke to me. For example, they thought that I had only been to a physiotherapist eight times, because I had been seeing a specialist physiotherapist in Brisbane. I was travelling to see her at my own expense because she is an expert in the management of Ehlers Danlos Syndrome. I was also attending a local physiotherapist and doing weekly small group physiotherapy. I was paying for most of this myself, with my own money.

58. The TAPIB stated that they couldn't consider my disability permanent because I had not trialled 'second-skin' garments to manage my disability. My physiotherapist told me these garments cost thousands of dollars. They are usually something funded by the NDIS. They had not been recommended by my medical team.

59. They also said some weird things, like that I was independent with a task (putting away shopping) because I could do it when my support workers were there. That's not independence.

60. They said that my wheelchair was ‘not evidence based’ despite being prescribed by an occupational therapist. Throughout the advice they said that a lot of things are ‘unclear’ that could have been clarified by speaking to me or my professionals. They based the judgement that I do not need a wheelchair off my diagnosis alone, without meeting me, or adequately considering my own allied health reports.

61. By this time I needed my wheelchair for all my mobility outside the house and also most of my mobility inside the home. I was using a custom manual wheelchair, which is an assistive technology item that can only be accessed through allied health prescription.

62. Telling me that my wheelchair was not ‘evidence based,’ despite being prescribed, while I was adjusting to the identity challenges that come with becoming more disabled and the access issues that are presented by wheelchair use was so hurtful.

63. I was very ashamed of needing to use a wheelchair as a young person. I already felt like people would think I was doing it ‘for attention.’ I felt unattractive and broken.

64. The TAPIB advice made me question myself even more, wondering if I had made this all up and was losing my grip on reality. I raised this over and over with my medical team. They did not agree with the NDIA. They said I was genuinely disabled. No one could quite understand why the NDIA were treating me like this.

65. I would like to make a complaint about the allied health professional who wrote this advice about me. Because of this advice, my appeal was not resolved at the conciliation stage in November 2024.

66. I became very depressed. For the first time in my life, I had thoughts about taking my own life. I started thinking that I hated myself and that my child deserved a better parent than me, and that I will never be able to have a fair go at life because I will always need to fight the NDIS for the things I need to move around my home or community. I have never had thoughts like this before. I have never experienced depression before. I felt completely hopeless and alone.

67. Over this period, I conservatively estimate that I spent more than $20,000 on physiotherapy, aids and equipment, specialist appointments, home modifications, travel from my rural location to Sydney and Brisbane for specialist appointments and other things I needed to manage my physical impairments, provide evidence for my NDIS appeal and continue caring for my son at home.

68. If it were not for having the responsibility of being a parent and the support of Legal Aid ACT, it is my opinion that I would have been at high risk for completing a suicide attempt as a direct result of the appeal process.

69. I left the ongoing job that I had. I was very passionate about that job and I was well supported there. I couldn’t cope anymore. I took many weeks off work entirely. Then I took a lower paying, fixed-term job that had less responsibility. It was all I could handle.

70. Legal Aid paid for me to have a medico-legal assessment with a very experienced physician. He said: 'my assessment based on the relevant experience of 60 years is that Mr Howson's functional disability is in the highest 2 – 3% of the community.'

71. A hearing was scheduled in the Administrative Review Tribunal on the 23rd July 2025.

72. On the 2nd July 2025, the NDIA offered to settle my matter in full.

73. They accepted that Ehlers Danlos Syndrome met the disability access criteria for the NDIS. They increased the value of my funded supports by more than $100,000. They resolved the matter entirely to my satisfaction, offering more than what I agreed to settle for at the conciliation in November.

74. The NDIA were not able to organise Terms of Agreement until the morning of the hearing. This in itself was stressful.

75. I was very relieved I did not have to go to hearing, but I was also really upset. It was July 2025. I applied to the NDIS for help in September 2023. I felt like I had lost two years of my life and two years of my kid's childhood.

76. The plan I have now is helpful, but because I was stuck for two years fighting for the support I needed in 2023, this plan doesn't fit my current needs. My disability has progressed further and I now have some mental health issues I didn't have before.

77. I am now only able to work two days a week, almost entirely from home and with a lot of accommodations. I don't know if I will be able to keep working. It's also only a temporary job and I don't know what will happen at the end of the contract in February.

78. My medical team have suggested that I apply for the Disability Support Pension. I want to emphasise that when I became disabled and applied for the NDIS, I was working in a secure job with some leadership responsibilities and a career path.

79. I no longer have the independence of driving around. Using inappropriate equipment and my inappropriate living situations has caused a lot of damage to my hands. I can't get my wheelchair in and out of the car anymore.

80. I still don't have grab rails in my bathroom or shower. I have to have baths because I have fallen in the shower, even with a shower chair I purchased myself, and am afraid of it happening again. I have to pull myself out of the bath and it's hurting me. To get up off the toilet I have to pull myself up using a window sill. It is hurting my hands and they are getting worse and worse.

81. The ramp to access my house is made from plywood. It was made for me by a friend.

82. I have been assessed as needing a power wheelchair because of my hands, but I'm only just at the beginning of this process. I am very afraid of what will happen when I make this request. I fear that the NDIA will not have added Ehlers Danlos Syndrome to my participant file, and that they will say I cannot have a power wheelchair because I am still on the NDIS 'for Autism.'

83. The NDIA are entirely in control of what is listed on my participant record as a diagnosis. They can change it at any time for any reason. There is no procedural fairness. This makes me feel powerless and misunderstood.

84. I still do not have an impairment notice.

85. I have worked in a number of professional roles, in the Australian Labor Party, in higher education, in the private sector and in a trade union. I have dealt with many different government systems. I have never experienced the level of profound and systemic dysfunction that I have seen in my dealings with the NDIA.

86. Every individual staff member I have dealt with, from planners, to enquiries team members, to Ms Rebecca Falkingham herself has been kind, generous and empathetic. However, the systems and rules they operate within seem to be unfit for purpose and not grounded in an understanding of disability.

87. I also have significant concerns that the TAPIB has outsized power, with almost no accountability. I see this as contributing to devastating results like the one I experienced. The person who wrote the ‘advice’ that delayed the resolution of my matter, caused a severe depressive episode of six months will never know me, and never know the impact that they had on me.

88. It appears to me that the TAPIB reinforces ideas about disability that are based in discrimination and prejudice. I would like to see careful examination of their work in relation to bias against women, gender diverse people, and people with less visible or less understood disabilities. I suspect that they often issue advice that diminishes the disabling experiences of women and gender diverse people and people with the types of disabling conditions most likely to impact women. I have no means of raising these concern about discrimination, or making an individual complaint about the allied health professional at the TAPIB who injured me. I would like the committee to investigate this and provide a clear complaints pathway for injured people. If the individuals working in TAPIB are allied health professionals, we must be able to complain to their regulating bodies and APRHA.

89. The concept that the help people need can be decided by a ‘primary disability’ reorients the NDIS away from inclusion and towards a segregationist model of disability support. It is also something that this committee has previously raised as a concern with the operations of the NDIA.

90. While the governing legislation has now been amended, the law says that impairments that meet the access criteria can be funded. At the moment, the NDIA has not told me what my impairments are. Throughout the entire ART process, we talked about diagnoses - which diagnosis was eligible for NDIS support, and which was not. I am not sure whether this approach has a basis in law.

91. The roll out of impairment notices has been significantly delayed. These notices were supposed to give people like me clear review rights when the Agency makes poor decisions about the nature of our disability. Without an impairment notice and the

review rights it facilitates, I have questions about how section 34(1)(aa) can function lawfully.

92. We don't need help to make our bodies and minds 'normal' according to an arbitrary definition. We need help to be included. This means looking at a person as an individual and trying to work out what barriers are preventing them from being included. When I applied to the NDIS in 2023, I was losing the basic ability to move around the community and my home. This is a huge potential risk to inclusion.

93. I mistakenly thought that the NDIS would support me when I needed it, build my capacity and get me the right equipment and support to continue to be an independent person. Instead, the NDIS wanted to give me expensive supports that would not help. If I had used these, that would have been a waste of government money.

94. I am now much more dependent than I ever have been. My hand function and mobility have declined a lot. I am more mentally unwell than I ever have been before in my life. This has coincided directly with my NDIS appeal and the delays in accessing appropriate support and equipment. I now rely on support workers for a lot of things.

95. The NDIA have caused profound harm to me. I have lost earning capacity, possibly permanently. I have lost years of my life to an appeal process that could have been resolved more than a year ago without intervention by the TAPIB.

96. My child was 8 when this started and soon he will be 10. My mental health has been improving since the appeal ended, but when I think about having to deal with the NDIA, for example, to apply for a power wheelchair or home modifications, I become very afraid and I experience despairing thoughts again.

97. The idea that the NDIA will soon be doing 'support needs assessments' and that these staff will not be allied health professionals, but the same planners making the decisions today fills me with panic. I am very concerned about the NDIA's use of automation and suspect that automation is the reason I received my first, disastrous NDIS plan that was not tailored to my needs or circumstances.

98. I want the NDIS to change too, but I don't think the NDIA can do this safely and competently without oversight, transparency and accountability.

99. I don't want 'special treatment.' I am nearly 35 years old. I want what most people my age want. I want to live in a house that is relatively safe and comfortable, where I can hop in the shower and meet most of my basic needs without hurting myself . I want my kid to have the best life possible. I want to go outside with my dog and watch him run around. I want to have friendships and be in love without having to burden my friends and partners with caring for me all day.

100. I do not believe that the NDIS is being run in a way that supports these goals. They spend a lot of money, including on me, without asking questions about what is going to be the best support to have someone be included in the community and have a life worth living.

101. Thank you for reading and considering this submission. I have made some recommendations on the next page.

Recommendations:

Recommendation 1:
The NDIA immediately provide current participants with a 'Notice of Impairment' and a team be set up specifically to amend these impairments at the internal review stage to avoid an unprecedented volume of Tribunal matters initiating simultaneously.

Recommendation 2:
That the work of the TAPIB branch undergo independent review, with the input of Disability Representative Organisations, to evaluate whether their operations have been subject to bias or discrimination, in relation to disability type, gender, sexuality, Aboriginality or any other form of bias. That staff at the TAPIB receive diversity training, that the work of individual TAPIB staff be carefully monitored for compliance with the UNCRPD, and that participants be enabled to make complaints to APRHA about the conduct of these allied health professionals.

Recommendation 3:
That all automated systems used by the NDIA to determine plan funding be open to democratic scrutiny through parliament.

Recommendation 4:
That the committee closely monitor the operation of these automated systems to ensure they are not based on diagnostic categories, but *impairments*, conceived broadly e.g. physical, cognitive, neurological. Diagnostic categories cannot be the basis for support planning in a Scheme oriented towards inclusion of people with disabilities.

Recommendation 5:
That an inquiry be undertaken into the NDIA's conduct as a model litigant in the Administrative Review Tribunal.

Recommendation 6:
That the NDIA's expenditure on external legal firms be capped to motivate early resolution of matters and ensure tribunal matters are only taken forward with reasonable chances of NDIA success.

Recommendation 7:
That the salary of the NDIS CEO and senior executive salaries be reduced substantially, with a bonus available but linked to the success of NDIA matters in the Tribunal and the minimisation of legal expenditure against people with disabilities.