**Annual Report No.1 of the 48th Parliament - NDIS**

**Submission**

**To the Honourable Chair**
**Joint Standing Committee on the National Disability Insurance Scheme**
**PO Box 6100, Parliament House, Canberra ACT 2600**

I make these submissions as Part of the Annual Report No.1 of the 48th Parliament – NDIS. This submission l wish to raise concerns the governance and administration of the NDIS. In particular it relates to the National Disability Insurance Scheme (Supports for Participants - Accounting for Compensation) Rules 2013.

These rules that are applied are unfair and unjust and leave persons with a disability, especially from workers compensation or road traffic accidents at a significant disadvantage where claims have become "ghost claims" due to the time period they have existed.

In normal circumstances, that have existed for approximately the previous twenty years or so, the process was a claim was established, injuries treated, injuries considered stable, impairment assessment undertaken and if a threshold for impairment was achieved then a common law settlement was made.

This would apply, ordinarily in the vast majority of claims and is largely how the system works today. Rightfully those common law settlements should provide adequate provision for on going co-payments of future treatment, were by the insurer, may also provide some co payment and on-going support; dependent on the terms of the settlement and the impairment rating. This is clearly the intent of National Disability Insurance Scheme (Supports for Participants - Accounting for Compensation) Rules 2013.

There is, however, no provision for claimants who were unable to access or seek a common law settlement and later experienced complications from their original injury that has led to a significant disability many years or decades later. This no doubt small group of claimants, may still have what is deemed an active claim with the insurer stating they will cover certain services, equipment or other needs. For the purposes of this submission, l will describe them as "ghost claims". The reason l use this term, is that although the insurer holds liability for provision of certain services, they also cap or limit the level of coverage. That is to say "approved rates". This for example, domestic cleaning is capped at $36 per hour. Compare this to NDIS which is $58 per hour. This leaves the claimant $22 per hour out of pocket for starters. If as many disabled people are on a fixed income such as a social security benefit, can quickly amount to $88 or more just for, based on 4 hours per fortnight cleaning if the service provider even charges the NDIS rate.

Many charge much higher. Then add, for example, the need for regular lawn mowing, similar rates can apply. It is easy to see someone being left $200 per fortnight or more out of pocket for basic essential supports. Most on a fixed income would simply be unable to afford this. This then brings into question, for example, if this person is living in a rental property, their tenancy could be in jeopardy because they are not able to adequately maintain the property to the required tenancy standards. Those same regulations prohibit you from closing off that claim even if you could.

If the insurer has capped the number of hours per week a person will be covered, there is therefore no provision for dynamic or unexpected sudden changes or the insurer can take months to determine what, if any, additional services they will provide.

The assumption is that the claimant can afford that $22 per hour (minimum) out of pocket rate because they have had a common law settlement. This, for example, could leave a wheelchair dependent claimant, with no formal or informal supports, trapped in their home without the provision of even basic housekeeping including bed changes for literally months. NDIS also bases all its assumptions on a common law settlement and will deny access to NDIS. This leaves the disabled person in a position with effectively no supports.

In regional and rural areas many service providers will not work with insurers who are not based in the state of service provision. The reasons including frustrations at trying to apply for "above rate payments" if that option even exists with insurers or greater profit margins and ease/certainty of payment found in the SaH or NDIS system.

We claim to follow the UN Charter for the Rights of the Disabled yet the disabled are segregated and denied services purely based on a perceived "responsibility" for their care when in reality that responsibility does not exist or exists in such a way it denies the support and care that person needs.

The governance and administration of the NDIA need to recognise and individualise the response to those persons who have these "ghost claims". There is provision in the NDIS legislation for CEO discretion but it is never exercised.

Solutions would include:

- Determine if a common law settlement has been granted in the previous twenty years.
- Determine and clarify what the responsibilities of the insurer and if and how they are actually working.
- Work collaboratively with insurers to recover the level of co payment they cap their services at and NDIS covers the difference – effectively providing access to the NDIS at a minimum based on what the insurer. NDIS manages this to ensure continuity and appropriate care provision for the claimant without having them disadvantaged. Prioritising the support rather than the bureaucracy and doing it with expediency that ensures continuity of care.

I have been granted a very limited plan, inadequate to my well documented needs, based on my other medical condition that has resulted in multiple strokes. The more recent diagnosis of CSVD (Cerebral Small Vascular Disease) has not been recognised despite it being a consequence of my strokes. My current plan has expired and NDIS has gaslight met since December and yet again l am now left with no support. I can guarantee you, no reasonable person would enjoy sleeping in the same bed sheets for weeks if they had any choice, be forced to decide what laundry to do because even doing one load exhausts you and leaves you needing to go to bed and that is before you have tried to get the washing in folded and put away. These are just minor examples but none of this matters to NDIS. You are just left to fall through the cracks and rot and most likely, hoped that you die so they can stop hearing from you and get another person off the NDIS. Trying to self-advocate and even deal with the NDIS when you are affected by a cognitive impairment is exhausting, humiliating and there is no recognition by the NDIS of the strain these places upon a claimant.

Further challenges with dealing with NDIS, is that Advocacy Services are state based. So if l am in WA, any state Advocacy service has no/ extremely limited understanding of the aforementioned Regulations let alone how the insurer, who could be interstate works. This happens even when trying to gain access to (limited) legal aid services and the trauma of dealing with the ART. They too add to your trauma by disclosing claimant's cases on their web site. This information, may for example, include disclosure of other medical conditions and even sexual trauma. The ART will also share this information with your insurer, without your consent and often deny on technicalities requests for confidentiality. This is retraumatising, gives insurers access to information they do not need to know and then they use that information against you to blame those medical conditions, for example, to further par back your claim as "contributing" factors or the like; thus trying to reduce their liability. Therefore, this acts as a deterrence to taking appeals to the ART, which is very difficult when you have a disability at the best of times.

When you are therefore dealing with the ART you are effectively thrown to the wolves. For NDIS clients, the NDIS should not be allowed to use lawyers, but senior managers should represent the NDIS except for the most complex cases, whereby a lawyer may be present to provide advice when needed. This would also save significant costs to the NDIS. A mediation process, with the support of the ART should be a priority; as should client's privacy. Clients do not, for example, need personal details such as incontinence issues publicly disclosed, or sexual trauma injuries disclosed. This l believe is abuse of the disabled. Many states have laws forbidding disclosure of sexual abuse and trauma in many circumstances within the provisions of their legal systems to protect victims. The federal court system does not. The client feels shame, embarrassment and humiliation along with the retraumatising from the events. NDIA needs to prioritise the protection of client privacy at a Commonwealth level and push for urgent legislative change, especially as it applies to ART appeals.

Changes need to be made to the system, the way its governed and administered, so ALL disable people are treated fairly and have equal opportunities in all aspects of dealing with the NDIA.

Thank you for your time.