

**JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY INSURANCE SCHEME
SENATE INQUIRY – INDEPENDENT ASSESSMENTS**

SUBMISSION BY:

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EXECUTIVE SUMMARY

I am the CEO of the Centre for Digital Business, a digital services and artificial intelligence company. I am an inclusion and accessibility advocate. I advise organisations globally, and speak and commentate on issues such as innovation, technology, digital identity, biometrics, co-design and artificial intelligence.

My background includes extensive public and private sector experience in Australia and internationally. This experience covers global technology strategy; policy development; major programme delivery; digital transformation; operational service delivery of call centres; web and digital services; face to face client services; large scale technology services; and global innovation.

In writing this submission, I am drawing on my somewhat unique experience: of lived experience in addition to my deep internal knowledge and experience as former Head of the NDIS Technology Authority.

I wrote the business case for the NDIS ICT systems, and for this to be based on co-design and the principles of the UN Convention on the Rights of Persons with Disabilities. I have an exceptionally deep knowledge of the NDIS processes, and the NDIS ICT system which were delivered by DHS. I have a deep understanding of NDIS capability, operating model and culture. I also have considerable operational knowledge of the cross government capability, systems and architecture on which the NDIS is dependent.

Perhaps somewhat unique, I believe there would be very few people with this deep level of direct internal knowledge of and experience in the NDIS operating environment, in addition to the lived experience of interacting with the NDIS.

My husband suffers a chronic genetic heart condition, with multiple heart surgeries. He has significant neurological and movement disorders and is losing the use of his hands.

My beautiful daughter has a complex and very significant combination of psychosocial disability and physical disability, and has suffered some horrific experiences. And two of my grandsons have cognitive and communication disability.

I detailed my continuing and very significant concerns with the NDIS ICT systems in a Submission to the Senate Inquiry into the NDIS ICT Systems (August 2018) outlining the issues, as I believed that no other independent commentator and person with both lived experience and internal experience would be able to. In that Senate Committee submission, I indicated further detailed information and references are contained in the internal report: "*Technology Authority Handover Report 9 June 2017*".

Additionally, I also provided a submission to the Joint Standing Committee Inquiry into the General Issues Around the Implementation and Performance of the NDIS (Committee Report December 2020). This submission was made together with my adult daughter, who is an NDIS participant. The purpose of providing that joint submission was to illustrate the far reaching and systemic deficiencies of the NDIS for people with psychosocial disability.

That submission described my daughter's catastrophic experience in dealing with the NDIS. Her two young sons, my grandsons, also have disability. My daughter's interaction with the NDIS has not only been tortuous for herself but has been exacerbated by the extreme anguish in dealing with the NDIS for her sons. My daughter made a detailed and harrowing personal statement in that submission, and I respectfully refer members of this Committee to her statement.

To reiterate from my previous submissions, I anticipated the trauma that my daughter would face and yet even with all my detailed internal knowledge and ability to engage solicitors, I could not prevent the damaging impact of my daughter's interaction with the NDIS.

There would be perhaps few other NDIS applicants or families who would have the insight at the beginning of their journey to make such detailed documentary recordings from the outset.

And yet, the systemic issues that I predicted and described in my previous submissions remain unresolved.

In the application of the proposed Independent Assessments, these systemic defects present an imminent threat to people with disability, especially people with psychosocial disability. My daughter now feels sheer terror at the prospect of being forced to endure an Independent Assessment.

I am grateful for the opportunity to provide this submission to the Joint Standing Committee Inquiry into the Independent Assessments under the NDIS.

- **Key Issues**

The Independent Assessment process is an utterly flawed, unethical and dangerous concept on every level. It is fundamentally different to the Independent Assessment concepts envisaged by the Productivity Commission and Tune Review.

The concept has taken hold as a result of the absence of an ethics framework in the NDIS legislation; an absence of an ethics framework in the NDIS governance; and no mention of ethics in any of the key corporate documents.

The lack of an overall ethics framework has serious implications beyond actuarial human research activities.

The lack of an ethics framework has implications for the evaluation of proposed interventions (policy and process) in terms of efficacy and safety; implications for operational effectiveness and consistency; implications for design; and implications for communications.

I will discuss each of these aspects with evidence in this submission.

In addition to the absence of an ethics framework there is an absence of co-design.

This means that the end-to-end human experience does not systematically influence design and nor is the human experience safeguarded by a robust and independent ethics framework. The human is out of the loop.

The systemic issues that I predicted and described in previous submissions remain unresolved, and I believe these are unresolvable for as long as these systemic issues are seen as “IT” issues to be fixed.

This submission details the root cause of inconsistency as the fundamental defects of the NDIS ICT Systems, processes and overall operating model as a consequence of the absence of an ethics framework and absence of co-design.

To reiterate once again, to achieve consistency, remediation has to start internally with the agency.

This submission also examines experimental whole-of-government digital activities, some involving banks, including facial recognition, blockchain and the broader application of algorithms.

The JSCNDIS needs to be alerted to the linkages between future blockchain and facial recognition applications as a means to control and monitor NDIS participants, and the risk that algorithms pose for people with disability in accessing services.

Algorithm generated robo-plans arising from the Independent Assessments are the first step.

The application of blockchain would see the robo-plan services transacted using blockchain programmable “smart money”. Access to these transactions for NDIS participants is likely to involve a facial recognition identity verification. Access to services for people with disability might be stopped by a negative but biased facial recognition algorithm.

The additive impact of these algorithm based services on people with disability needs to be seriously examined.

The absence of an ethics and co-design framework exposes NDIS participants to potential human rights violations from these experimental whole-of-government digital activities.

Of great concern and detailed in this submission, are distressing and widespread examples of unethical and unsafe communication practices.

In this day and age, that a government agency can forcibly and arbitrarily subject people with disability to lifelong examination, monitoring and study – via an intervention that has been shown to damage people - without any oversight or ethics framework cannot be tolerated by civil society.

RECOMMENDATIONS

1. Immediately stop the Independent Assessment action.
2. Establish an ethics framework within the NDIS legislation.
3. Establish an ethics committee as part of the NDIS Board governance arrangements.
4. Establish independent oversight by the Joint Standing Committee on the NDIS and the Australian Human Rights Commission, of any activities involving biometrics, algorithms or blockchain in services for people with disability.
5. Initiate a complete re-engineering, re-architecting and re-build of NDIS systems: and for this re-engineering exercise to be determined through co-design.
6. Establish an ongoing in-house co-design capability, resourced by staff with disability and advocacy sector experience.

ETHICS

There is an absence of an ethics framework in any of the key corporate documents, NDIS governance or NDIS legislation. The lack of an ethics framework has implications beyond the conduct of actuarial research activities, to include implications for service design, systems architecture, process integrity, communications and critically, the avoidance of harm.

Whilst the NDIS Data Sharing Policy talks about the role of the NDIA Research and Evaluation Office (REO), the submission of Ms Cummins questions why standards in relation to human research are not applied by the NDIA:

[REFERENCE: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities. Submission by Muriel Cummins, AHPRA-registered Mental Health Occupational Therapist, page 9]

*“Should **an external body** seek to complete a study using the same methodology as outlined in the IA pilot, researching NDIS participants, they would be required to adhere to the National Statement on Ethical Conduct in Human Research (NMHRC, 2018), and the study would be overseen by an independent Human Research Ethics Committee (HREC) [9]. Human Research Ethics Committees oversee ethical conduct in research practice, including, but not limited to: ethical research process; evaluation of risk of participants; informed consent; data and record management; publication of findings; conflict of interest; and the handling of allegations of research misconduct [9]. **Why do these research standards not apply to research undertaken by the NDIA?**”*

Ms Cummins’ excellent submission raises serious questions of governance in the conduct of human research, and I concur with Ms Cummins’ position that the actuarial driven Independent Assessment process meets the criteria for a human research exercise.

My contention is that the apparent lack of an ethics framework encompassing the overall NDIS operating model has implications beyond actuarial research activities. The absence of an ethics framework affects the culture, tone and operations of the agency in the administration of the scheme.

The absence of an ethics framework has implications for the evaluation of proposed interventions (policy and process) in terms of efficacy and safety; implications for operational effectiveness and consistency; implications for design; and implications for communications.

All proposed changes must be evaluated within an ethics framework and with the same rigour required to support decisions about the introduction of new medical interventions.

My further contention is that co-design is essential to an ethics framework. It is also noted with concern, that in addition to the absence of mention of an ethics framework in any of the key corporate documents, there is also an absence of mention of co-design in these documents.

It is further noted that the NDIS Board governance arrangements do not appear to include an ethics committee.

This means that the end-to-end human experience does not systematically influence design and nor is the human experience safeguarded by a robust and independent ethics framework.

I strongly reiterate and repeat the conclusions and recommendation of Ms Muriel Cummins submission:

[REFERENCE: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities. Submission by Muriel Cummins, AHPRA-registered Mental Health Occupational Therapist, page 12]:

“That immediate consideration be given to ceasing or suspending the current IA pilot, due to the likely risk of harm outweighing benefits to people with disability, and not resume without the oversight of an independent Human Research Ethics Committee (HREC).”

Ms Cummins submission is extraordinarily thorough in its depth of analysis: revealing the depth of the lack of transparency; lack of analysis; lack of ethics framework; and considerable and known risk of harm.

In this day and age, that a government agency can forcibly and arbitrarily subject people with disability to lifelong examination and study – an intervention that has been shown to damage people - without any oversight or ethics framework cannot be tolerated by civil society.

Effectively, the NDIA is proposing to undertake human research driven by an actuarial doctrine, without ethics oversight. ***This is verging on human experimentation.*** The view that this can happen and be justified on flimsy “actuarial” grounds has to be exposed and quashed.

ACTUARIAL OVER-REACH AND LACK OF CO-DESIGN

Whilst the NDIS is an insurance scheme that funds services, the NDIA as an organisation is also in the business of servicing. However, the essential capabilities of service design and co-design do not exist in the NDIA.

Together with the lack of an ethics framework, the lack of co-design and service design capabilities are the root cause of most of the NDIS operational and servicing problems.

The Committee must rectify this.

The original business case funded an ongoing co-design capability to be established and built up within the agency, staffed by NDIA staff (not consultants) including staff with disability. Core to the purpose of the NDIS, co-design is necessary as an ongoing capability – not an activity to be undertaken by consultants or via periodic reference groups. As stated above, co-design is not mentioned in any of the current corporate documents.

In the absence of a co-design capability and ethics framework, there is an over-reach of the actuarial function influencing NDIS systems, services and processes. “User testing” is not the same as co-design.

The human is out of the loop: the single most significant cause of system defects and failures.

The actuary function does not provide expertise in *service design*. These are fundamentally different and specialised areas of expertise but equally necessary for ethical governance, and safe and ethical operations.

In addition to the extraordinary and known risk inherent in commencing the intervention of Independent Assessments in the absence of an ethics framework, the statistical methodology discussed at Senate Estimates is flawed.

There is no way that an unknown person – in a 20 minute interview - could comprehend the magnitude, severity and fragility of my daughter’s psychosocial and physical disability. Or any persons. Her condition so significantly fluctuates. And for that to somehow provide “consistency” is ludicrous. Further commentary on the notion of “consistency” and psychosocial factors is provided below in the section “*Psychosocial*”.

Furthermore, the statements of the NDIA at Senate Estimates regarding the satisfaction survey following the Independent Assessment pilot program, demonstrate an appalling lack of survey design and its application in a servicing setting involving vulnerable people.

Compliance, or acquiescence, is a well-known psychological response for people (and especially vulnerable people) dealing with the power of bureaucratic institutions and this compliance factor skews survey responses. People just say yes. Inclusion Australia has noted the acquiescence factor is a critical issue for people with intellectual disability, and the assessment tools do not take this into account.

There is decades of international peer reviewed research on this. People feel enormous pressure; confusion; and intimidation. They do not understand the complex concepts. People are anxious and many cannot understand the nature of the questions or the significance of their responses.

Not only were the number of responses not statistically significant, but the responses from participants and their families would likely be invalid due to the compliance factor.

This defective survey design and misrepresentation of “findings” from pilot activities occurs because there is a lack of an ethics framework. This would have to call into question any actuarial analysis or forecasting based on such questionable “findings”.

PSYCHOSOCIAL

The NDIA has repeatedly stated that it has a “psychosocial pathway”. This is a specious statement to be vigorously challenged. The NDIA simply does not have the culture nor the capability to manage the psychosocial caseload.

It beggars belief, that a government agency can baldly claim it has a “psychosocial pathway” and at the same time proceed with an intervention such as Independent Assessments – which has been shown to damage people, including suicide – without any apparent concern regarding the necessity of an ethics framework.

This is either organisational ignorance and incompetence or wilful action that chooses to ignore the known risk of harm to people with disability. The lack of an ethics framework is evidence of the mendacious claims to a “psychosocial pathway”.

I believe this is a very significant safety issue for people with psychosocial disability. It is our experience that the NDIA processes are not safe. The lack of an ethics framework and organisational disinterest in co-design is continuing evidence of this.

On my daughter’s initial application, the NDIA lost her entire NDIS application - including the 400+ pages lever arch folder of medical evidence. It would be more than two years before she would be accepted into the NDIS and have a plan.

As we have documented in extensive details, my daughter’s condition worsened very significantly during the whole NDIS application and review process. Not only was my daughter initially refused the supports desperately needed (due to the NDIA administrative stuff-ups) and suffered and struggled for almost two years in the cruellest way – but my daughter and her psychiatrist both questioned whether it was worth damaging her mental health even further.

As her mother, and with the inside knowledge of the NDIA as to what was causing these issues for my daughter (and others), this situation was incredibly traumatic for me. Persevere and have the system damage my daughter’s mental health, or give up and have my daughter and her family denied justice.

This was a sickening Faustian bargain.

I anticipated the trauma that she would face and that’s why I took photos at the beginning of this nightmare journey - and yet with all my detailed internal knowledge and ability to engage solicitors - I could not prevent the damaging impact of my daughter’s interaction with the NDIS.

As stated previously, there would be perhaps no other NDIS applicant or family who would have the insight at the beginning of their journey to make such documentary recordings from the outset.

Excerpts from our previous JSCNDIS Submission:

[REFERENCE:

<https://www.aph.gov.au/DocumentStore.ashx?id=89789756-4056-4fbf-a37b-ecf6ea5d567d&subId=673978>]

“In addition to the photos we took at lodgement, we have maintained a detailed chronology and analysis of the various interactions with the NDIS. This chronology shows that on TWELVE times, information was provided/re-sent/re-requested.

The NDIS admits to not having all the documents, and inconsistencies on the part of the NDIS as to what they had and when they received it.

In total, more than 30 medical reports and assessments have been provided to the NDIA over the past 22 months as part of a seemingly never-ending process of application and review, describing in extensive detail, the diagnoses and impacts of my daughter's long-standing, complex, significant and permanent psychosocial disability.

My daughter's treating psychiatrist has provided three written statements specifically addressing the NDIS; and my daughter's general practitioner has provided two written statements specifically addressing the NDIS. In addition there are five psychologists' reports including a detailed clinical assessment and needs based assessment addressing the NDIS criteria. There are five letters from sleep disorder specialists, and detailed reports from bariatric surgeons, dieticians and eating disorder specialists including an eating disorder psychiatrist. All this is in addition to the almost 20 years of medical history provided.”

....

“Of great concern, my daughter's condition and her function has significantly worsened over the almost two years since the original NDIS application was made – across all her health, functioning and social dimensions. My daughter's worsening situation has been documented in statements by her treating psychiatrist, psychologist, eating disorder specialist and sleep disorder specialist. The NDIA was informed on multiple occasions of my daughter's significantly worsening situation, with no response.”

...

“The NDIS does not have the culture nor the capability to manage the psychosocial caseload. The complex needs and circumstances of people with psychosocial disability are being processed and examined by NDIS staff who have no experience or professional background in this area.

Our family experience and evidence is that over a protracted period of time, the NDIS psychosocial support team and NDIS psychosocial pathway processes - simply do not exist.

Various statements in public documents on the NDIS website, in the media and in public forums - regarding the improved psychosocial "pathway" - is utterly false. If there was any truth to the statement that there was an improved psychosocial pathway, then my daughter would not have suffered this damaging and traumatic experience over a protracted period of time. "

To reiterate our statements in previous submissions, which describe in detail my daughter's catastrophic experiences in applying for and dealing with the NDIS, all this underscores the sheer terror that she feels at the prospect of being forced to endure an Independent Assessment.

And for what purpose? And what "safeguards" are there in place that would anticipate such adverse reactions.

None.

It would appear that the actuarial doctrine which has driven such systemic complexities and inconsistencies – and through which my daughter has horrifically suffered - will somehow be made "more consistent" through a 20 minute outsourced high-risk arrangement.

My daughter is not an actuarial experiment.

And nor is any other participant or family.

Following my daughter's appeal and acceptance into the NDIS, her experience with the LAC for the planning process was equally traumatic and de-humanising.

This is an excerpt of our email correspondence with the LAC, detailing my daughter's treatment at her planning meeting.

"Today's meeting was set up a month ago, as soon as [my daughter] received her NDIS Access Approval letter. As we mentioned in the meeting, the process of assembling the documentation, and the application and Internal Review process took more than three years and involved us engaging solicitors as the NDIS had lost [my daughter's] application and documentation.

The NDIS Access Approval Letter, stated that [my daughter] should commence preparing for the planning meeting - we have actually been planning for this meeting for a very long time, given [my daughter's] very complex condition and range of disabilities.

When [my daughter] booked today's appointment a month ago, she asked that the meeting be with a planner with psychosocial disability experience. [My daughter] called a number of times to confirm this - most recently last Friday, when planners were changed and you were included into [my daughter's] planning meeting.

So approaching today's meeting, [my daughter] was extremely agitated and stressed.

From my perspective, given that the NDIS encourages participants to prepare for the planning meeting, our expectation is that you and [LAC organisation] should have been similarly prepared given the advanced notice of this planning meeting. You were clearly unprepared and had not read [my daughter's] extensive file. A chat for a few hours does not cover the extent of her circumstances and needs - including safety considerations.

Given the NDIS and government emphasis on better supporting people with psychosocial disability in navigating the NDIS, today's meeting was grossly unacceptable on many levels. The whole meeting was a form filling box-ticking exercise to generate a plan at the end of this one meeting - we appreciate that you are operating under the directions of [LAC organisation], but we felt incredible pressure to push on to complete the planning meeting, even though we have been going for nearly two hours and [my daughter] was clearly unwell. Your comment that there is only one planning meeting, and we appreciate this is the [LAC organisation] approach, is inconsistent with statements made by the NDIS - that participants have the opportunity to have a number of planning meetings to ensure that their circumstances have been understood and an appropriate amount of time has been invested in developing a plan."

Our deep concern today with this rushed, apparently KPI driven approach, is that [my daughter's] documentation had not been read beforehand and [my daughter] was unwell and not coping. [My daughter] was not even offered a glass of water or a break.

We appreciate that you have scheduled a second planning meeting for [my daughter] this Friday. As I mentioned, there is still a lot to go through and I would like to flag the possibility of the need for a third planning meeting after Friday. The reasons for this potential third meeting are outlined below - and I reference the attached documents which are the documents in the red folder we gave you today. A number of these documents should be on the NDIS system, but we assembled these in the red folder as a focus of the planning discussion today.

[My daughter] has requested that you read all the documents attached in this email (documents from the red folder today), before we meet again on Friday. [My daughter] also requests that you confirm if you have access to the 30 documents and medical reports referred to in the NDIS letter granting [my daughter] NDIS access and read these before Friday's meeting."

My Daughter's Personal Statements. From Application, Review and Planning

"This document combines three separate personal statements that [my daughter] has made over the course of the past several years, through the NDIS application and review process. The three statements have been scanned into the one document. These statements provide significant detail of [my daughter's] life and her day to day - and [my daughter] has described in significant detail the types of supports required, against the various sections of the NDIS legislation. What [my daughter] discussed today in terms of goals and statement of supports, was not a wish list but developed using the various guides provided by the NDIS. [My daughter] requests that you read her personal statements before Friday - if you are unable to do so, [my daughter] would prefer that the meeting is rescheduled to another time to make sure that you have read the documents given this is essential to the planning process."

And all this interaction was with a planner who the LAC organisation stated had experience in psychosocial disability as a mental health nurse.

My daughter was forced to state over and over again the extraordinarily intimate details of her complex disability – a humiliating, dehumanising and traumatising experience - to a stranger - who had not even read her file and in a process absolutely compromised by time pressure.

This is the traumatic experience which I believe will be the experience with the Independent Assessment process. The traumatic process is then re-experienced when the LAC discusses the results of the Independent Assessment at the planning meeting, but the person is not able to challenge the results of the report.

Given the systemic process defects that my daughter suffered over a protracted period of time, this is a terrifying prospect for her as a person with complex psychosocial and physical disability.

The person is subjected to the trauma of the Independent Assessment with a stranger and then is forced to endure the trauma of an LAC planning exercise also with a stranger to again go over the intimate details of their life.

And with the absence of an ethics framework, what happens when things go wrong in the Independent Assessment process? This will happen. This happened to us in the LAC planning exercise as I have described above. There was no-one to help us as we faced a very grave situation caused by the process. Quite the contrary, there was pressure for the process to continue at all costs.

Just "stopping" is not the answer and certainly not enough. What care and supports are provided to the person and their family?

The whole person must be considered and this takes time – time clearly that the outsourced LAC planning arrangements do not provide for. And time that a contracted "Independent Assessment" also does not provide for. And for people with complex disabilities and co-morbidities, the theoretical notion of a "disability agnostic" process runs counter to the multi-faceted determinants of the "whole person".

This "disability agnostic" concept appears to be a continuation of the actuarial fiction of "primary disability" that has created so many problems for people with disability in accessing the NDIS and being provided with the necessary supports.

Significantly, the submission by Ms Cummins challenges the NDIA statements regarding the applicability of “disability neutral” assessments.

[REFERENCE: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities. Submission by Muriel Cummins, AHPRA-registered Mental Health Occupational Therapist page 5.]

“The NDIA has indicated that the use of the same assessment across all disability types is supported by the World Health Organization International Classification of Functioning, Health and Disability (ICF). This not the case. [Emphasis added]. While the ICF does encourage disability-neutral conceptualisation of function, it does not support a disability neutral approach to assessing and measuring functioning and disability. Rather, it supports recognition of the variance of disability across a range of disability types. “

And in the effort to avoid “sympathy bias” – a pejorative statement lacking any evidence - the Independent Assessment introduces biases that are grossly more damaging. That is, dangerous biases driven by the considerable time pressure, KPI pressure and a “disability agnostic” paradigm that compromises the consideration of the whole person – as my daughter experienced during her initial planning process.

Furthermore, it matters not that the concept of Independent Assessments was part of the original Productivity Commission vision of the NDIS, when the NDIS core data architecture, systems and processes are so defective. The Independent Assessment model as proposed by the NDIA is in any case fundamentally different to that envisaged by the Productivity Commission and Tune Review.

The original Productivity Commission vision also envisaged an agency workforce of 10,000 staff and an emarket. It would appear that the government is picking and choosing and re-marketing elements of the original Productivity Commission vision in an attempt to overcome the broader systemic organisational and scheme deficiencies.

What is needed to bring about consistency is not to pick and choose from the original Productivity Commission vision, but for the NDIA to *first* get its internal house in order.

And the pre-eminent actions must be to immediately stop the Independent Assessment process, and establish an ethics framework within the NDIS legislation together with a significant and urgent investment in an in-house co-design capability.

SYSTEMS AND PROCESSES

I have detailed in previous submissions to this Committee, the fundamental defects of the NDIS ICT Systems, processes and overall operating model. To reiterate again, all the issues I indicated would happen, have happened.

The systemic issues that I predicted and described in my previous submissions remain unresolved, and I believe these are unresolvable for as long as these systemic issues are seen as “IT” issues to be fixed.

Excerpts from our previous JSCNDIS Submission:

[REFERENCE:<https://www.aph.gov.au/DocumentStore.ashx?id=89789756-4056-4fbf-a37b-ecf6ea5d567d&subId=673978>]

“It is my combined lived experience and professional view, that the NDIS requires complete re- engineering, shaped by comprehensive and on-going co-design. The issues are far-reaching and systemic and not something that can be sorted with ICT “fixes”.”

Apart from the human rights and privacy violations which I have written about in detail, these systemic issues are so deep and irreversible, that the fundamental actuarial premise of the Scheme is, I believe, questionable.

It is a widespread experience that letters get sent without a name or date; as well as documents and letters with incorrect names and NDIS numbers. We and other people receive other people’s letters. Text messages and phone calls about *other* participants. Documents that get sent to the NDIA continue to get lost.

This simply should not be possible.

- **Privacy Not Architected**

That this happens at all is evidence of defective data architecture and processes, which are not only the root cause of inconsistencies, but create serious exposures in the management of health and other critically sensitive information.

This is not only our personal experience, but is a widespread experience described by many people in the NDIS Grassroots Facebook Group; by a great many advocacy groups; and is documented in countless submissions by other people and organisations to inquiries of this Committee and other inquiries.

An ethics framework is fundamental to the design of systems and processes. It creates a control framework for design and causes fundamental questions to be asked about the operating model.

Excerpts from our previous JSCNDIS Submission:

[REFERENCE: <https://www.aph.gov.au/DocumentStore.ashx?id=89789756-4056-4fbf-a37b-ecf6ea5d567d&subId=673978>]

“There are very serious questions to be asked about why detailed and highly sensitive medical and personal documents and records are repeatedly lost. There are further questions about the control framework and application of standards for the protection of health information.

These documents and records - covering the most sensitive personal and family information - are far more sensitive than the medical records held by My Health Record.”

Given our direct personal experience of documents that have been sent directly to the NDIA, being *repeatedly* lost – a common experience of a great many people – there is serious cause for concern as to how extremely personal information collected by a stranger in the Independent Assessment process will be protected.

Indeed, there is considerable lack of transparency as to how data collected during the assessment process by the independent contracted assessor, will be safeguarded, stored and transmitted in outsourced arrangements that are complicated by bespoke and complex system processes.

Ms Cummins documents her concerns on transparency, privacy and data management:

[REFERENCE: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities. Submission by Muriel Cummins, AHPRA-registered Mental Health Occupational Therapist page 11]

“There are also concerns about data storage as IA consent information states that the IA pilot data is stored outside of Australia, where Australian privacy laws do not apply. This appears to be a possible breach of NDIA policy that states: “When we use third parties, such as community partners and other contractors, to perform certain functions, the third parties are contractually required to work in accordance with the Privacy Act and the NDIS Act, and to access and store all personal information using our IT systems, not their own.”

If the purpose of the proposed Independent Assessments is about consistency (which is not defined), then systems with such defective data architecture are fundamentally incapable of achieving such consistency.

As stated above, in the absence of a co-design capability and ethics framework, there is an over-reach of the actuarial function influencing NDIS systems, services and processes. “User testing” is not the same as co-design.

The human is out of the loop: the single most significant cause of servicing system defects and failures.

The NDIS systems are laboriously architected for complexity and bespoke processes as a result of the human being out of the loop. ***With the human out of the loop, privacy by design is impossible.*** The consequence of this is illustrated by the horrific examples throughout this and my previous submissions, and the submissions of many other people and advocacy groups.

What I bring to this discussion, is knowledge of what is causing this.

The only way to bring about consistency, starts with the complete re-engineering, co-design and re-build of the NDIS systems, processes and operating model. To achieve consistency, the remediation has to start internally with the agency and an ethics framework must be included in the NDIS legislation.

- **Defective Catalogue Assets**

The deep co-design and ethics directed re-engineering required is not an IT exercise. This is beyond the technical swap-out of the SAP system for the Salesforce CRM: a swap out which will not address the systemic design defects of the overall operating model described in this and previous submissions.

To illustrate this issue, in previous submissions and in internal advice to the NDIA, I have highlighted the appalling situation of one of the most critical elements of the NDIS services infrastructure: **the catalogue** (price guide and support catalogue). The lack of design drives confusion and inconsistencies.

[REFERENCE: Excerpts from our previous JSCNDIS Submission:

<https://www.aph.gov.au/DocumentStore.ashx?id=89789756-4056-4fbf-a37b-ecf6ea5d567d&subId=673978>

“There is a lack of design, a lack of accessibility standards and no functionality in the catalogue, one of the most essential and relied upon elements of the NDIS. The catalogue urgently requires complete redesign, re-engineering and to be built as a functioning element of services infrastructure.”

The catalogue is comprised of extraordinarily dense PDF, word and CSV table documents that have no intelligence; are not interactive; are not explanatory; and utterly fail accessibility standards. These catalogue assets also fail to comply with any catalogue standard such as the United Nations Standard Products and Services Code (UN/SPSC). As a consequence, the catalogue assets not only drive a significant red tape overhead for providers who have to manually interpret the data and manually manipulate the data into their systems, but are incomprehensible for participants.

A level of incomprehensibility that makes a mockery of the UN Convention on the Rights of Persons with Disabilities.

Significantly for the NDIS, the maintenance of the catalogue assets is highly manual and resource intensive: and maintained in such a manual way, is highly prone to error because there is no effective control framework. The array of static historical versions, addenda and explanatory documents in various formats nested in the NDIS website, creates a multitude of transparency and traceability problems for providers, participants and legal processes.

All this drives horrendous inconsistencies and complexity throughout the whole system.

As per my original advice, this is not how a catalogue should be designed or operated. And over time, the continuing growth of historic versions of static documents nested within layers of the NDIS website does not support a transparent time series analysis of the movement of prices. This is not a future-proof strategy for this critical element of services infrastructure.

And given the inconsistencies driven by the complex bespoke static catalogue assets, it very difficult to contemplate how the proposed robo-plans arising from the proposed Independent Assessments, would practically work.

Re-engineering of the catalogue assets is necessary before any catalogue related API service would be possible. And this can only happen with an end-to-end co-design involving participants, providers, advocates and catalogue design specialists.

HUMAN RIGHTS RISKS FROM WHOLE-OF-GOVERNMENT “DIGITAL” ACTIVITIES

The absence of an ethics and co-design framework exposes NDIS participants to human rights violations from experimental whole-of-government digital activities.

The reason why I am examining the following whole-of-government digital activities here, is that these are being pursued by government and the NDIA at the same time as the Independent Assessment proposal. And there are linkages between these activities.

To reiterate once again, to achieve consistency, remediation has to start internally with the agency. Imposing experimental whole-of-government digital activities into an environment where the data architecture, processes and key services assets (such as the services catalogue) are defective is unethical. The very absence of an ethics framework is evidence of this.

- **Blockchain And Payments**

The NDIA participated in a blockchain proof-of-concept undertaken by the Digital Transformation Agency (DTA) and the Commonwealth Bank.

Having been one of the instigators of Payment Delivery Reform in 2009 which eventually led to the RBA work on the New Payment Platform, I well understand payments processes and risks, and the benefits of innovation in payments and information services.

However, I am equally concerned with on-the-ground use, civil liberties and what happens when things go wrong.

Given the horrendously complex NDIS environment, defective processes and vulnerable people, there needs to be considerable caution in the application of blockchain technology. Blockchain in itself – as with other technology innovations – does not address fundamental design and human rights issues. Ethics is paramount.

The involvement of the Commonwealth Bank itself raises further ethics issues, given the value of participant data; the size of the market; and the yet to be realised emarket honey pot of data, funds and services.

The report on the “Making Money Smart” blockchain proof-of-concept report makes no reference to an ethics framework. Whilst there are several general references to “transparency of funds”, there is no reference to the transparency of the underlying blockchain.

So in a not too distant future scenario, a participant would be served a robo-plan, arising from an Independent Assessment, with the robo-plan services transacted using blockchain programmable “smart money”.

Far from participant choice and control, there would be no transparency to the Independent Assessment; no transparency to the robo-plan algorithms or rules; and no transparency as to the blockchain algorithms.

Whilst there is no transparency or effective appeal rights for the participant, the system would achieve real-time and pre-emptive life-long monitoring and control of NDIS participants by the government.

Whether by intention or inadvertence, this is a dangerous future emerging without governance or ethics.

- **Facial Recognition and Digital Identity**

In addition to the concerns about the lack of an ethics framework on blockchain activities, the application of facial recognition technology in the access to services has significant human rights implications for people with disability.

To reiterate, the reason why I am examining whole-of-government facial recognition activities here, is that these are being pursued by government as part of service delivery, at the same time as the Independent Assessment proposal. There are linkages between these activities and the additive impacts of these algorithm based services on people with disability needs to be understood.

Facial recognition technologies have become problematic for democracy and civil society. The European Commission, as well as in many US cities, have banned the use of facial recognition in public areas. Microsoft and Amazon have banned police from using their facial recognition systems.

In 2020 IBM announced that it would no longer offer, develop or research facial recognition technology.

According to Arvind Krishna, the chief executive of IBM worldwide:

[REFERENCE: <https://www.cnn.com/2020/06/08/ibm-gets-out-of-facial-recognition-business-calls-on-congress-to-advance-policies-tackling-racial-injustice.html>]

“We believe now is the time to begin a national dialogue on whether and how facial recognition technology should be employed by domestic law enforcement agencies.”

“Artificial Intelligence is a powerful tool that can help law enforcement keep citizens safe. But vendors and users of AI systems have a shared responsibility to ensure that AI is tested for bias, particularly when used in law enforcement, and that such bias testing is audited and reported”.

One of the most controversial activities being progressed by the DTA, and which will have significant impact on NDIS participants and people with disability seeking access to the NDIS, is the myGovID facial recognition project.

According to the DTA, facial recognition will be required for citizens to access more confidential services, under what the DTA calls identity proofing level three (IP3) – which requires facial verification and liveness detection – or proof-of-life test.

According to the trusted digital identity framework, IP3 provides “high confidence in the claimed identity and is intended for services with a risk of serious consequences from fraud”.

As I wrote in InnovationAus “Face Recognition, Function Creep and Democracy”, facial recognition technology can be very bad for people with disability including people with movement disorders and people with darker skin colour.

[REFERENCE: <https://www.innovationaus.com/face-recognition-function-creep-and-democracy/>]

“The problem with this “proof-of-life” concept, is the variability of results (I would say discrimination) in relation to people with disability, people who are infirmed, and people with darker skin colour. In any case, the reasons why “proof-of-life” might be needed is highly contentious – and the assumption needs to be tested by engagement with civil society especially in the context of government service delivery.”

The JSCNDIS needs to be alerted to the linkages between future blockchain and facial recognition applications as a means to control and monitor NDIS participants, and the risk that algorithms pose for people with disability in accessing services.

Algorithm generated robo-plans arising from the Independent Assessments are the first step.

The application of blockchain would see the robo-plan services transacted using blockchain programmable “smart money”. Access to these transactions for NDIS participants is likely to involve a facial recognition identity verification. Access to services for people with disability might be stopped by a negative but biased facial recognition algorithm.

The additive impact of these algorithm based services on people with disability needs to be seriously examined.

Fraud risk might be stated as the justification, whereas it is the intractable complexity of the NDIS concepts, systems and processes that are the root cause of confusion by both participants and providers.

To again emphasise, in order to achieve consistency, remediation has to start internally with the agency. Imposing experimental whole-of-government digital activities – which are not governed by ethics or co-design – will result in a surveillance servicing system where algorithms embed biases causing harm to people with disability.

This Committee, the Australian Human Rights Commission and civil society ought to be alert to and seriously concerned by these activities.

COMMUNICATIONS

The consequence of a lack of an ethics framework is also evident in the manner in which the NDIA communicates with participants and their families. The following examples are taken from online forums and communications from the agency, demonstrating the extent of the compromised and unethical communications with participants regarding the Independent Assessment process.

There is extensive peer-reviewed research internationally over many decades regarding the negative impact of bureaucratic government and healthcare communications and correspondence on access to justice and services, and its negative impact on life outcomes in vulnerable and disadvantaged populations.

The effect and impact of all the communications needs to be considered holistically, and overseen by an ethics framework. The examples below paint a picture of confusion; pressure; institutional power imbalances; discrimination; lack of accessibility; unethical practices; and a battle over “misinformation”. Again to emphasise, this communication is targeted at vulnerable people with disability, many of whom have psychosocial disability and other impairments.

It is immensely distressing to discuss the following sections, given the vulnerability of many people with disability.

- **Scam and Grooming-Like Approaches**

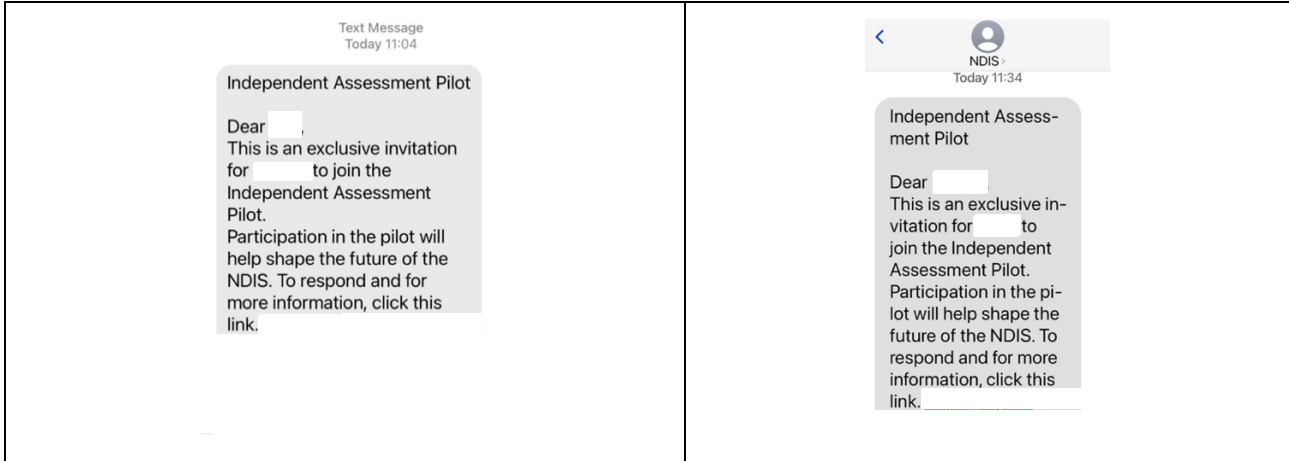
The following examples show text messages that have been sent to participants by the NDIA, effectively “luring” them into participating in the Independent Assessment pilot. An “exclusive invitation” message of the type typically used in retail promotions and of greater concern, used in identity scams, financial scams, and grooming and exploitation.

It is utterly unethical and verging on maladministration that this type of communication is used at all, let alone in communications *targeted* at people with disability, and which would include vulnerable people with psychosocial disability. Who approves and designs this type of communication? This is a direct consequence of the lack of an ethics framework and lack of ethics oversight more broadly.

The Office of the eSafety Commissioner and agencies involved with promoting cyber security and safe online practices, explicitly warn people about such scams and grooming approaches. Their efforts are to raise awareness of safe online practices, to build resilience and to educate the community, schools and families about the dangers of online predators to life, welfare and finances.

The scam-like approaches used by the NDIA in these text messages to participants about the Independent Assessments is not only counter to the efforts of the Office of the eSafety Commissioner, but exposes participants to harm more broadly by creating confusion as what is or is not a scam. It is a common tactic of scammers to impersonate a “government” message, luring people to click on links. This practice would be a cyber security exposure for participants as well as the agency.

An ethics framework would say that such dangerous scam-like approaches are not to be used.



Another equally concerning aspect of this “exclusive invitation” and data collection tool, is the lack of transparency about how the data is transmitted and where the data is stored. As stated earlier, Ms Muriel Cummins has raised similar concerns.

Once the link is clicked, the information provided in the form states that the provider server is located in Canada. A check with both Hosting Checker and Check-Host, identify the server as hosted by Cloudflare, Inc in Chicago.


Transparency is needed as to whether NDIS participant information is transmitted and stored offshore: this could raise privacy and security issues, and the complex issues around data sovereignty. This in addition to the significant data defects of the NDIS systems as discussed thought out this submission.

Generic statements about a secure server in Canada and that all this is being done in accordance with the Privacy Act is inadequate for people to make an informed decision regarding opting-in and the risks that this might involve. Furthermore, there is considerable confusion as to whether a person is opting-out or signing-up: this is a typical tactic of scammers.

Most people, let alone a great many vulnerable people with disability, simply would not understand the issues at hand and this is why an ethics framework is critical. However, it is not apparent whether or not there has been ethics oversight or other governance such as a Privacy Impact Assessment for this process. Participants and their families have the right to be informed.

- **Scam-Like Approaches + Incorrect Data**

The combined effect of the scam-like approaches together with the defective data architecture (described in the section under “Systems”) creates other unknown exposures and risks for participants.

<p>received one (well 2) for my participants - incorrect names with NDIS numbers. Opted out on line, rang and opted out and still received 2 phone calls to discuss - again opting out for both on both calls..... waiting for the next round of calls/emails where they have ingored participants wishes, claiming nothing recorded on their records, even though I gave the receipt numbers of phone call interactions, and date the email was sent.</p>	<p>These are two examples of widespread instances where the messages contained incorrect names and NDIS numbers about other people. Such data defects are a common and systemic issue, which has been documented in previous submissions.</p>
<p> Yesterday 2 Plan Nominees (for same PWD) received messages inviting the PWD to participate in the trial. 1 invited Heath,1 invited Peter, yet his name is neither. Not a professional start.</p>	<p>These many examples illustrate fundamental privacy, security and data integrity weaknesses. Not only are these actual examples of data and privacy breaches, but it shows the impact of the defective data architecture, systems and processes in terms of the time and effort that people have to go through, and the operational costs of the never ending cycle of emails, calls and follow-ups.</p>

There appears to be no effective control framework to safeguard data integrity nor of the many processes - such as opt-in processes, document management, and personal communication with participants – that are dependent on it. Together, the lack of an ethics framework and lack of co-design create the conditions for this to happen.

- **NDIS Outward Bound Calls**

The outward bound call regime further demonstrates how detached the NDIA communication ethos is from the needs and circumstances of people with disability they are serving. Calls that have no identification number. Scripts that immediately ask about a participant. As with the scam-like “invitation” text messages, these are the type of phone scams that lure people into divulging personal banking and financial information.

Furthermore, the following examples show how the instructions given by participants about how they need to be communicated with are consistently ignored or mismanaged.

In the first example below, the commentary describes the experience of people with brain injury and stroke survivors being subjected to complex scripted outward bound recruitment calls about the Independent Assessments. The experience was described as “overwhelming”.

Extensive commentary in online forums and in other submissions, indicates that this is a common experience for people living with psychosocial disability, cognitive impairment and intellectual disability.

Of great concern, not only does this person’s commentary point to fundamental issues of lack of accessibility – overwhelming content, long and complex web addresses – but the overwhelming experience that potentially deprives people of the ability to advocate for themselves. People’s human agency is compromised.

In the second example, a hearing impaired person describes the continuing communication problems of receiving phone calls and voice mail messages from the agency – that they cannot hear – even though this person has requested communication via email.

In the third example, the discussion continues about a blind person receiving a written letter about the Independent Assessment.

People are concerned that they will be exited from the scheme because they miss responding to the Independent Assessment invitation.

These are not isolated instances. To the contrary, these are widespread.



This is systemic discrimination that undermines the rights of people with disability by the very agency that should be an exemplar.

Two years of outsourcing has systematically entrenched discrimination on the basis of disability.

I pointed this exact problem out more than two years ago in my submission to the JSCNDIS Inquiry into the NDIS Systems (August 2018). I stated:

“The NDIA sends letters to people who physically can’t open them, and to people with a cognitive disability who cannot understand the bureaucratic language. Letters, forms and brochures point to the website which is not searchable; to the portal which does not meet the communication and accessibility needs of a great many people; and call centre which cannot meet the needs of people who are non-verbal or have cognitive impairment.

Many people with psychosocial disability find it traumatising to call the call centre, even the prospect of doing so. Many participants with a cognitive disability are not able to remember what was said to them over the phone, and either call up multiple times or are too afraid or anxious to call at all.”

That is more than 2 years ago, and with all the costs and sophisticated statements about the outsourced capacity of the call centres, people with disability are not only *not* being supported but are *prevented* from understanding major changes that directly affect their life. If people’s instructions about how they need to be communicated with are so consistently ignored or mismanaged, then it would appear that the Quarterly Report of the call centre performance is not the complete picture.

- **Complex Bureaucratic Communications and the Power Imbalance**

As stated previously, there is decades of peer reviewed research on the adverse impact of official bureaucratic communications on vulnerable people in the access to justice and services. And the depth of the impact of this communication can only be appreciated when seen in the context of all communication and interactions, and the recipient’s situation and disabilities.

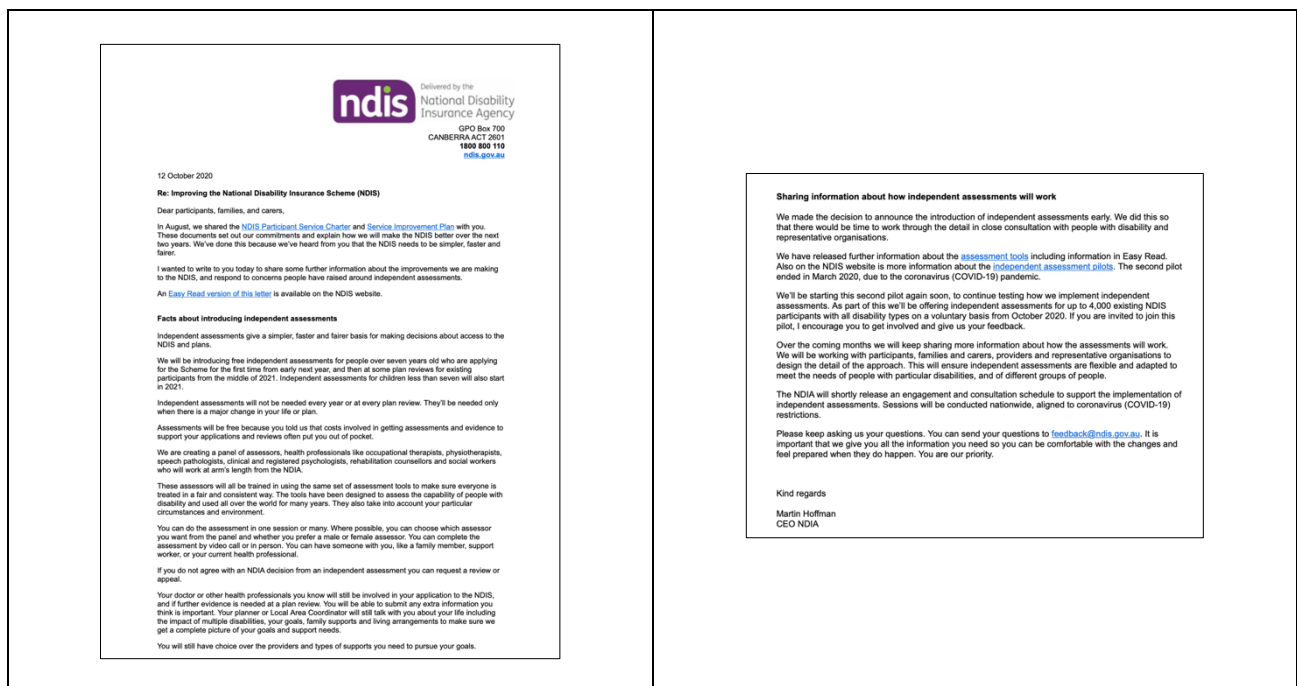
The following is an example of a complex and unanticipated correspondence regarding the Independent Assessments from the CEO to my daughter, which has triggered deeply alarming fear and terror. Other participants have also received this letter.

Such correspondence direct from the CEO needs to be considered in context. This is a powerful letter. A long bureaucratic letter from the chief executive, *the delegate*, triggers fear and anxiety. There is a visceral power imbalance.

For many participants, their struggle to gain access to the NDIS has been drawn out and traumatic, as was the case for my daughter. These type of letters and communication cause people to live in fear.

And notwithstanding the availability of an easy English version, such complex detailed and lengthy communication – with complex concepts such as assessment tools – is incomprehensible for most people. The easy English version does not resolve the underlying issues.

These are major changes which the participant does not have any control over nor understands, and the complexity of the changes and the chaos of all the communication negatively impacts their quality of life.



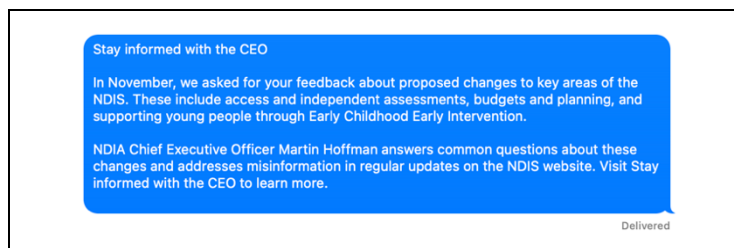
- Claims of “Misinformation”

The following message that was made into the NDIS Participant Portal. The message confronts the participant – who has already been bombarded with information from the NDIS - with the notion of “misinformation”.

Again, for people with intellectual disability, cognitive impairment or psychosocial disability, the very notion of “misinformation” presented in official communications is concerning. This is especially so when the notion of “misinformation” is presented in the context of complex concepts that impacts a person’s life. Trust is fragile.

What is the psychological state of someone accessing the portal; stressed with the seemingly never-ending interactions with the NDIA; official letters; and then being confronted with the notion of “misinformation”.

“Misinformation” is a concept that would not be understood by many people, and at the same time it is a concept that is highly politicised in a battle for trust.



There is no argument with the fact that the NDIA has a legitimate and critical role to play in the provision of information. But the needs, circumstances and experiences of people with disability fundamentally must shape how this is done. Their community and their family are their tribe: this is where trust and acceptance exists.

The effect and impact of all the communications needs to be considered holistically: including all other experiences the participant has had with the NDIS.

Of great concern, the distressing examples provided in this section paint a picture of confusion; pressure; unethical practices; discrimination and exclusion on the basis of disability; institutional power imbalances; lack of accessibility; privacy exposures; and a battle over “misinformation”. And all this involving the most vulnerable people in our community.

What is not clear, is what is the nature and purpose of the communication. Is it consultation? Is it providing information? Or is it recruitment for human research trials? Compounding the overwhelming complexity of the concepts presented, the nuances of the different purposes are subtle and are not understood by most people, let alone by people who have suffered institutional abuse, and people who are vulnerable and disadvantaged. Informed consent is simply not possible.

To reiterate again the compelling commentary from the submission of Ms Muriel Cummins to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities, questioning why research standards and oversight of an independent Human Research Ethics Committees do not apply to research undertaken by the NDIA:

[REFERENCE: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities. Submission by Muriel Cummins, AHPRA-registered Mental Health Occupational Therapist, page 9]

*“Should **an external body** seek to complete a study using the same methodology as outlined in the IA pilot, researching NDIS participants, they would be required to adhere to the National Statement on Ethical Conduct in Human Research (NMHRC, 2018), and the study would be overseen by an independent Human Research Ethics Committee (HREC) [9]. Human Research Ethics Committees oversee ethical conduct in research practice, including, but not limited to: ethical research process; evaluation of risk of participants; informed consent; data and record management; publication of findings; conflict of interest; and the handling of allegations of research misconduct [9]. **Why do these research standards not apply to research undertaken by the NDIA?**”*

The principles of the UN Convention on the Rights of Persons with Disability and the principle of “Nothing About Me, Without Me” is fundamental to how communication is shaped and conveyed. And for communication to be contextual, effective and trust safeguarded, co-design with participants, families and community is essential. This is not consultation: consultation does not overcome power imbalances; erase memories of institutional abuse; nor earn trust.

What the distressing examples have shown in this section on “Communication”, is the absence of an ethics framework and the absence of co-design create the very conditions for abuse and discrimination to occur.

PERSONAL STATEMENT: MR ALLAN JOHNSON (FATHER)

“As [my daughter’s] father I care deeply about the terrible impact her disability has had on her life over the years. She is a gentle caring soul who would do anything for anyone. I myself have several chronic illnesses and disabilities and know just how difficult it can sometimes be to just get out of bed, let alone do everything that a growing family needs.

The years we fought alongside [our daughter] against the NDIS simply to get her into the scheme have left me emotionally scarred. At a time when I was too ill to work, we had to find a way to pay expensive legal fees simply to help [our daughter] obtain her human rights, and her entitlements under Australian law. And yet the years of work, expense and suffering by [our daughter] and family, and the extensive efforts of her remarkable medical team, appear to be at risk from what amounts to a short interview by a bureaucrat or commercial contractor without any of the qualifications and experience that have gone into diagnosing [our daughter] and developing the therapies and supports she urgently requires every minute of every day.

My own chronic illnesses and disabilities are continuously managed by a medical team including GPs, pathologists, specialists, therapists and other allied health professionals. My condition, and therapies including medications, are regularly reviewed to make sure my care is to the latest standards and adjusted as my condition progresses. All of my conditions, like [our daughter’s], are lifelong conditions and don’t miraculously disappear. Unlike [our daughter] though, my reviews are by my highly skilled medical team. I am not subject to some arbitrary review by a bureaucrat or commercial contractor whose motivation might be to reduce services to disabled and or otherwise ill individuals to meet some set of KPIs that do not include [our daughter’s] long-term health and quality of life.

Let me tell you something that you must understand. Chronic illness and disability are not ‘steady state’. There are many days when you lie in bed wishing the world would go away. There are (rare) other days when life is almost normal, whatever that normal is for someone with a heavy burden of illness and disability. A snapshot on a pre-scheduled day, especially by a stranger, has no scientific basis. You will not be invited into someone’s home on the days when life is not worth living. The appointment will be cancelled on those days. You will only get to see someone when they feel they have the energy to go through what will be a frightening and draining process. To believe otherwise suggests that a deep misunderstanding of the nature of chronic illness and disability.

My final comment is that many people with chronic illnesses and disability, like me, have been, or are being, treated for anxiety and depression. Whenever we meet with our medical team, they quietly assess our emotional state at the start and completion of our sessions. This is a highly skilled task. If they believe that our emotional state is fragile during a session be that a diagnosis, therapy or simply a discussion of our progress, they don’t walk us out the door to let us deal with it ourselves. That is exceedingly dangerous. They use their skill and training to help us at the time and if they believe there is any risk to our wellbeing will take appropriate steps be that hospitalisation or other. Human life is too fragile to be left in the hands of strangers without deep medical experience.”

SUMMARY

The NDIS Independent Assessments will not “level the playing field” as stated by the NDIA: this is a sweeping and specious statement. These will in fact, cause immense trauma and disadvantage for people with disability and their families. It will cause reviews and appeals that will clog the administrative and legal system for years.

The greatest cost will be the lives and well-being of NDIS participants and their families. And the research and analysis of Ms Cummins of similar programs overseas is confronting. The research reported that functional capacity assessments are associated with significant increase in harm *including suicide* for people with disability—particularly people with psychosocial disability experiencing socioeconomic disadvantage.

Ms Cummins submission cited: B Barr, D Taylor-Robinson, D Stuckler, R Loopstra and A Reeves, "First, do no harm": are disability assessments associated with adverse trends in mental health? A longitudinal ecological study', Journal of Epidemiology and Community Health, Vol. 70, No. 4, 2015:

“[In] England between 2010 and 2013, just over one million recipients of disability benefit had their eligibility reassessed using a new functional checklist. A...study concluded that the program of reassessing people on disability benefits using the checklist was independently associated with an increase in suicides, self-reported mental health problems and antidepressant prescribing.”

The Independent Assessment process is an utterly flawed and unethical concept on every level.

The actuarial doctrine behind it is flawed. The communications with people with disability and their families is unethical and has eroded trust. Persistently, the NDIS systems have been shown to be incapable of supporting even the most fundamental processes; to the contrary, the NDIS systems complexity and defects exacerbate disadvantage. And yet again, the NDIA has demonstrated that it has no regard for nor capability regarding the needs and circumstances of people living with psychosocial disability.

To reiterate.

The Independent Assessment model as proposed by the NDIA is fundamentally different to that envisaged by the Productivity Commission and Tune Review. And that is information that needs to be communicated clearly to everyone.

The original Productivity Commission vision also envisaged an agency workforce of 10,000 staff and an emarket. It would appear that the government is picking and choosing and re-marketing elements of the original Productivity Commission vision in an attempt to overcome the broader systemic organisational and scheme deficiencies.

What will save participants costs, time and trauma is for the NDIA to get its house in order *first* and to bring about consistency in its processes, communication and transparency in decision making.

With my internal knowledge, I anticipated my daughter's traumatic experience in accessing the NDIS and documented this in previous submissions. It now sickens me with full knowledge and in anticipation that the Independent Assessment process will proceed in spite of all the health and professional evidence to the contrary.

This will cause immense trauma perpetrated by government on its most vulnerable citizens in full knowledge of the evidence that these processes cost people their lives.

Effectively, the NDIS is proposing to undertake human research driven by an actuarial and political doctrine, without evidence and without ethics oversight. ***This is verging on human experimentation.***

Australian civil society must not tolerate the actions of government that forcibly and arbitrarily subject people with disability to lifelong examination, study and monitoring. History is a reminder of where these actions can lead. That this control of people with disability will be effected through technologies such as biometrics, algorithms and blockchain is anathema to a harmonious and inclusive civil society and the human rights of all people.

The NDIS was fought for by the community for our families and their futures. There is much at stake.

RECOMMENDATIONS

1. Immediately stop the Independent Assessment action.
2. Establish an ethics framework within the NDIS legislation.
3. Establish an ethics committee as part of the NDIS Board governance arrangements.
4. Establish independent oversight by the Joint Standing Committee on the NDIS and the Australian Human Rights Commission, of any activities involving biometrics, algorithms or blockchain.
5. Initiate a complete re-engineering, re-architecting and re-build of NDIS systems: and for this re-engineering exercise to be determine through co-design.
6. Establish an ongoing in-house co-design capability, resourced by staff with disability and advocacy sector experience.

Marie Johnson
CEO
Centre for Digital Business Pty Limited

BIOGRAPHY: MARIE JOHNSON

Marie Johnson is the CEO of the Centre for Digital Business. She is an accessibility advocate, and a recognized global speaker and commentator on artificial intelligence; technology; digital services; ehealth; cyber; identity; biometrics; and innovation.

An internationally experienced entrepreneur, Marie has an unparalleled track record across the public and private sector delivering significant technology, innovation and digital services transformation programs encompassing revenue, business, social services, payments, identity, immigration visa operations and disability services. The diversity of roles covers service delivery operations, global technology industry strategy, Chief Information Officer, Chief Technology Architect, board director and advisor. Marie was the Head of the Technology Authority of the National Disability Insurance Agency.

Marie conceived and led the global co-design effort with people with disability to deliver “Nadia” the first AI powered digital human for service delivery. Grounded in human rights, this work sparked a global industry and appetite for AI powered digital humans.

Following Nadia, Marie designed and created the artificial intelligent “Digital Human Cardiac Coach”, introduced at the global Singularity University Exponential Medicine Conference in San Diego November 2019.

The strategic framework “Co-Design for AI @” which she developed, embeds Human Rights in service design.

In addition to large scale service delivery operations, Marie has led the strategy and implementation of significant reform programs across the digital machinery of government:

- Australian Business Number (ABN) registration in joint task force with the ATO.
- The Business Entry Point, initiative of the three levels of government.
- Chief Technology Architect for the \$1Billion Health and Human Services Access Card programme.
- Collaboration with the Reserve Bank of Australia on innovation in payments and information services initiating Payment Delivery Reform.
- Service Delivery Reform technology business cases bringing together Centrelink, Medicare Australia and Child Support.
- Developed and delivered the \$700 million Visa Pricing Transformation (VPT) programme; and delivery of the Global eMedical system to 100 countries in partnership with Citizenship and Immigration Canada at Department of Immigration and Citizenship (DIAC).

Marie was influential in the Australian Financial Systems Inquiry, which recommended the need for a federated digital identity framework as a critical element for the future robustness of Australia’s financial systems.

The government and digital initiatives Marie has led have been also been recognised globally.

These include the United Nations Public Service Award in the category “Application of ICT in government: government” for the Business Entry Point (www.business.gov.au) which she led for 5 years.

In 2005, the US Government awarded Marie an *O-1 Visa* (Individuals with Extraordinary Ability or Achievement) to take up the role leading *Microsoft’s Worldwide Public Services and eGovernment business*, including Microsoft’s Identity Strategy in Government. Microsoft noted Marie’s egovernment knowledge “...is unique in the world and is of particular interest to Microsoft as we pursue our egovernment strategies”.

In 2006-2007, Marie was named “Innovative CIO of the Year – Australia”. In 2013, Marie was named one of Australia’s “100 Women of Influence”. In 2019, was awarded the “Exceptional Woman of Excellence” at the Women Economic Forum (WEF) in Perth. WEF is the largest gathering of women entrepreneurs & leaders worldwide.

For many years, Marie was an invited member of the Accenture Global CIO Advisory Council; an Independent Member of the Australian Federal Police Spectrum Programme Board; and an elected National Board Director of the Australian Information Industry Association. In 2019, Marie was faculty at Singularity University Exponential Medicine (San Diego).

Marie served as an Inaugural member of the Australian National University (ANU) Cyber Institute Advisory Board.

In 2020, Marie delivered the 2020 Kenneth Jenkins Oration to the National Disability Services National Conference.

In 2021, Marie is the Patron of the Tech Girls Movement Foundation. www.techgirlsmovement.org

Qualifications

MBA (Melbourne Business School); Bachelor of Arts; Harvard University Kennedy School of Government Senior Executive Fellows Program; and Graduate of Australian Institute of Company Directors

More Information: www.marie-johnson.com

REFERENCES

- **Joint Standing Committee on the National Disability Insurance Scheme: ICT Systems. Submission by Marie Johnson, Centre for Digital Business**
<https://www.aph.gov.au/DocumentStore.ashx?id=f3ea66e3-e39c-42bc-b4d3-ded2f415d0a6&subId=659057>
- **Joint Standing Committee Inquiry into the General Issues Around the Implementation and Performance of the NDIS. Submission 17. Marie Johnson and Daughter, NDIS Participant.**
<https://www.aph.gov.au/DocumentStore.ashx?id=89789756-4056-4fbf-a37b-ecf6ea5d567d&subId=673978>
- **Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities. Submission by Muriel Cummins, AHPRA-registered Mental Health Occupational Therapist**

Ms Muriel Cummins Occupational Therapist, *Submission 48*, p. 3. Ms Cummins cited B Barr, D Taylor-Robinson, D Stuckler, R Loopstra and A Reeves, "'First, do no harm": are disability assessments associated with adverse trends in mental health? A longitudinal ecological study', *Journal of Epidemiology and Community Health*, Vol. 70, No. 4, 2015.

- **Blockchain Case Study: Commonwealth Bank and the NDIS.**
<https://www.dta.gov.au/help-and-advice/technology/blockchain/do-you-need-blockchain/blockchain-case-studies/blockchain-case-study-commonwealth-bank-and-ndis>
- **Face recognition, function creep and democracy. By Marie Johnson. Published in InnovationAus, 9 June 2020.**
<https://www.innovationaus.com/face-recognition-function-creep-and-democracy/>
- **IBM gets out of facial recognition business, calls on Congress to advance policies tackling racial injustice. CNBC. 8 June, 2020**
<https://www.cnbc.com/2020/06/08/ibm-gets-out-of-facial-recognition-business-calls-on-congress-to-advance-policies-tackling-racial-injustice.html>
- **Inclusion Australia submission on NDIS Independent Assessments, February 2021.**
<https://www.inclusionaustralia.org.au/wp-content/uploads/2021/02/Inclusion-Australia-submission-on-Independent-Assessments-FINAL.pdf>