Firstly, I would like to acknowledge the traditional owners of the land on which we meet, and pay my respects to their elders past and present.

Secondly, I would like to thank Australian Unity for the invitation to join you today.

Australia Day is an opportunity to celebrate our national story, to reflect on the people and events that have shaped our nation and to consider how our shared future might unfold.

Today, I would like to reflect on the history of people with disability in Australia, including the creation of the National Disability Insurance Scheme.

No doubt many of you have read the numerous newspaper columns on progress of the Scheme to date. And those are important stories and insights about how the Scheme is operating.

But, today I wanted to take the opportunity to pause and reflect on why the Scheme was created in the first place and share with you the journey we are all taking to support people with disability to live with autonomy, self-determination and dignity.

I was born in Queensland in the 1950s. I was one of five children and when I was six weeks old my parents discovered that I was blind.

At that time, it was practice to place blind children in a specialist school at a very young age to provide them with the skills and knowledge to prepare for life. So, from the age of 4 until 14, I would only return home for weekends and school holidays.

For the last four years of high school, I lived at home and attended a regular school.

I had very supportive parents who placed no limitations on what I could achieve, and my four siblings were very vocal about the fact that blindness wasn’t a good enough excuse to get out of doing the household chores.

I studied mathematical statistics and IT at university, lived in share houses with friends, travelled the globe and have spent most of my life gainfully employed. I’ve also raised four children, one of whom is blind, and recently welcomed my first grandchild.

When I reflect on my story, I can think of many barriers that I have had to overcome to achieve what I have achieved. But—there is one thing that my family always gave me, which is also the key theme of today’s breakfast—and that is the dignity of risk.

From an early age, I was allowed to make decisions, take risks, fail—then get back up and try again.

When I was in my final year of school, I decided to study mathematics. I was advised by a so called expert that I should not study mathematics as I was a blind female and I might fail. At age 17, my immediate response was “I have the right to fail”!

But, I was one of the lucky ones.

Australia has a long history of poor treatment and segregation of people with disability. It wasn’t so long ago that we were referred to as halfwits, retards, invalids, cripples and spastics.

Sociologists claim that our negative attitudes towards people with disability can be traced back to ancient Greece and Rome, where people with disability were considered to be sinners that were possessed and morally corrupt.

Reliant on family or charity, the vast majority of people lived—and continue to live today—in extreme poverty.

The funding of disability support by Government first occurred in 1601, when the Poor Laws were passed by the UK government. These laws created a requirement for the collection of local taxes to provide food to the impotent poor. But even with this support, food was still scarce and many people lived short lives.

More significant intervention started to occur in the 1880s including in colonial Australia, as governments began to build large institutions to provide a cradle-to-grave place to live. Here, people with disability were housed for their entire life—away from shame, fear and the dangers of the outside world.

I'm sure many of you have heard of the Kew Cottages, or what was originally known as the Kew Idiot Asylum. This is but one example.

Like many institutions throughout Australia's history, these were frequently the scenes of horrific sexual, physical and psychological abuse.

I sure that most people here today have some idea of the neglect and abuse that went on in these institutions, but I imagine many of you will be surprised to learn that they still exist today.

The NSW Government is currently in the process of closing the Stockton Centre, and Victoria is also in the process of closing its final three institutions in Colac, Sandhurst and Oakleigh.

In these institutions, these individuals live in shared rooms, with shared bathrooms—and many have never left the walls of their institution.

It is not uncommon to hear people express the view that people with a disability are better off in an institution because they can be with their own kind. But, as a person who was segregated from society when I was a child, I can assure you that this has never been, and will never be the case.

The 1970s saw a flurry of government-initiated inquiries, with the Henderson Poverty Inquiry finding that "handicap is the greatest single cause of poverty in Australia".

Deinstitutionalisation commenced, and social services policies were targeted at including people with disability in the community through education, employment, housing and inclusion services. The 1980s saw the creation of the Disability Services Act 1986, and the 90s saw enactment of the Disability Discrimination Act in 1992.

One could have been forgiven for thinking that Australia's world-class social services system met the basic needs of people with disability.

But, in 2009 a report by the disability community called 'Shut Out' began to shed light onto the exclusion of people with disability from our society.

This was followed by the 2011 enquiry by the Productivity Commission into Australia's disability system, which revealed that the vast majority of people with disability were still living in abject poverty and were not getting the services they needed.

The Productivity Commission's opening remarks were as follows.

Current disability supports are inequitable, underfunded, fragmented and inefficient and give people with a disability little choice. They provide no certainty that people will be able to access appropriate supports when needed. While some governments have performed much better than others, and there are pockets of success, overall no *disability support arrangements in any jurisdiction are working well in all of the areas where change is required.*

The Productivity Commission recommended the creation of a National Disability Insurance Scheme to provide a coherent national system for disability support that would remove the defects of the current arrangements.

In Australia, approximately 4 million, or one in five people, have a disability.

Of these 4 million people, only around 460,000 are expected to be eligible for the NDIS. We refer to these people as participants.

Every participant is a person that has a significant and permanent disability, and will likely require support for the rest of their lives.

The main goal of the NDIS is to support people with disabilities and their families to live ordinary lives—including working and living in the community.

Each participant is provided with an individualised budget, which they can spend on supports and services that relate to their disability—under the NDIS Act, this is referred to as 'reasonable and necessary support'.

The adoption of individualised budgets for people with disability is a fundamental shift in the way that disability support is provided. Prior to the NDIS, disability providers received millions of dollars in government funding to deliver services—but these services were rationed, and you got what you were given, which was rarely enough.

Under the NDIS, participants are able to shop around, choose their service provider and get the best deal for themselves. For the disability sector, which is used to receiving block grants of funding from the government, this is a dramatic change to their operations. Now, providers must offer participants real choice and compete with other providers in order to keep their clients.

The NDIS is often referred to as the greatest social reform since Medicare, and that is significant acknowledgment of its scale and ambition. But, the NDIS is also fundamentally different to Medicare—it is not just about fixed payments determined based on an objective set of criteria. Instead, it is a payment made to an individual, based on individual needs and circumstances. I for example, prefer to use a white cane to move around. But another blind person may prefer to use a guide dog, which is far more expensive than my little white cane. But that is their choice.

To a certain extent, the NDIS is a worrying proposition for a community that has grown used to a budgeted, as opposed to needs based approach to support funding. Unlike our current welfare payment systems, it requires us to put our faith in the hands of people with disability and trust that they will spend their tax payer funded budgets wisely. Most of the time it will be spent well, but sometime people with make the wrong choice. But that is the risk we must face as a community—how much dignity would we remove to also remove the risk of poor choices?

I have sketched today some of the sad history that drained all dignity from the lives of those with disability. But do we have the courage and generosity as to persist with a new approach? Or will we fall back on old ways?

Almost 120,000 adults and children with severe disabilities are currently benefit from the NDIS and are being supported to do every day things such as riding bikes, learning to drive, catching a bus and visiting the library.

For some, the NDIS has meant small but important changes to their lives, such as access to a support worker for daily showers, instead of three times per week despite daily incontinence.

For others, it has meant the ability to take make big choices, such as living independently for the first time.

I’d like to share with you some of my favourite stories.

Tom is 22 and recently got his first part time job. Prior to becoming an NDIS participant, he only received enough funding for 15 minutes of support each day – enough to get him out of bed, but not enough to get him out of the front door and to work. Now his is also funded to get dressed for work so he can do what many people with disability openly say they aspire to do—to pay taxes.

Joe is a seventeen year old with Down syndrome. Each fortnight, Joe’s support worker takes him to the supermarket where he uses a list to buy ingredients for a meal. He operates the self-serve checkout and uses his ATM card to pay. The worker teaches Joe to stay focussed while they prepare the meal, and they always take photos as they go so that Joe has a visual recipe book for next time. Joe hopes that learning these skills will mean that he will be able to move out of home when he is older.

Cassie is the mum of a young child with special needs, and is also studying at university. The Scheme was able to support a local childcare provider to learn how to manage her son’s needs, so that he could stay close to home and in a mainstream service, just like any other child.

While there are many amazing human stories about the NDIS, it is also important to understand the financial model that underpins the scheme, which is based on investment and insurance principles.

The NDIS is the first Commonwealth social services program to use an insurance model to monitor its costs. To give effect to this model, the National Disability Insurance Agency has a team of actuaries that are constantly identifying cost pressures and their underlying causes, enabling the management team to make adjustments as required.

The other important aspect of an insurance model, is that it enables the upfront investment in supports for a person where it will lead to an overall cost reduction.

For example, a young man with a spinal cord injury previously needed the support of two care workers to assist him in and out of bed and with daily activities. Under the NDIS, a ceiling hoist was installed in his home, which is being used to assist his mobility with the support of just one carer. This change immediately reduced his dependence and the level of intrusion into his life, while also reducing the costs of supporting this young man by more than $1 million over his lifetime.

This is but one example of the transformative effects that education, training and new equipment and technologies can have, both on the lives of participants and the long-term costs of the Scheme. It is also a practical example of an investment and insurance approach at work.

The Productivity Commission recently reviewed the costs of the NDIS, and confirmed that it was broadly on track and in-line with the Commission’s original estimates.

The Commission recognised that an insurance approach requires upfront investments, which do not necessarily fit with the standard four year government budget cycle.

To conclude my address today, I want to share with you what keeps me awake at night as a person with a disability, the mother of a son who is blind, and a life-long disability advocate beyond the NDIS – that is, that we still have so far to go in making our society one that is inclusive and affords dignity to people with disability.

To the chair of the NDIS Independent Advisory Committee, Rhonda Galbally:

An NDIS package cannot force schools to be open and accepting of people with disability.

An NDIS package cannot force employers to hire people with disability who are just as capable as their able-bodied peers.

An NDIS package cannot make the public transport system and buildings accessible.

And an NDIS package cannot change the societal perception that people with disability are better off with their own kind in segregated settings.

At the National Disability Insurance Agency, we are working with participants, governments and the community to ensure that people with disability are afforded the dignity of risk. But to achieve genuine change, we need to think differently as a society.

So, as my final point, I would ask that each of you consider how you will take up the challenge of ensuring our society is one that is genuinely inclusive of people with disability.

Will it be employing more people with disability? Supporting your kids to become playmates with someone with a disability? Or even just smiling and saying hello when you see a person with a disability on the street.

I usually don’t feel saintly enough to quote Mother Teresa, but there is one saying of hers that always resonates with me: I alone cannot change the world, but I can cast a stone across the waters to create many ripples.

Thank you again to Australian Unity for inviting me today to talk about a topic that I am deeply passionate about. To finish, I’d like to propose a toast to maturing our nation’s future.