

National Disability Data Asset Webinar Highlights Video Transcript

Voiceover

- National Disability Data Asset webinar highlights [title screen]

Mel Butcher (Social Deck)

- Today leaders from the disability community will explain the purpose of the National Disability Data Asset and benefits for different groups as governments move closer to agreeing on the build of the National Disability Data Asset.

Voiceover

- Benefits of the National Disability Data Asset [title screen]

Dr Ben Gauntlett (Australian Human Rights Commission)

- The benefit of the National Disability Data Asset is broad. It benefits not only people with disability, their family members and people who support them, government, researchers, and also organisations that seek to assist people with disability in the community.
- And what the National Disability Data Asset can do is make invisible needs visible by linking previously disparate datasets in a way that ensures that we can assess, not only what need exists in the community, but also the outcomes of policy endeavors or potential policy endeavors to seek to ensure that people with disability are given the ability to lead a dignified life.

Catherine McAlpine (Inclusion Australia)

- So when we talk about data, we know well these days that more than 1 in 6 Australians have a disability. What is far less well-known is there are about 460,000 people who have an intellectual disability, and currently we are unable to put the number on how many people with an intellectual disability are students in mainstream schools or have jobs in the open market, let alone how many people with an intellectual disability might be in jail, or who have limited access or no access to support for decision making.
- And even the NDIA who over the past decade has amassed much, much more data than we had before, is not able to tell us how many NDIS participants experienced both an intellectual disability and autism.
- These are very specific examples that show how currently governments don't have a complete picture of how people with disability are supported by all the different levels of government and agencies.

Paul Hardcastle (Department of Social Services)

- This is a data asset that will bring in the data of all Australians so that we can see how people with disability are faring compared to people without disability. It is necessary to measure a range of things in Australia's disability strategy, that looks at the difference between those two cohorts and the National Disability Data Asset will be providing some key information for Australia's Disability Strategy.

Voiceover

- How it will work – linking data [Title screen]

Dr Ben Gauntlett

- So the way how the asset works is that it takes existing datasets which are de-identified and links them.

Dr Scott Avery (Western Sydney University)

- The asset will be collecting de-identified, that means your name will not be on it from a range of sources, So the Institute of Health and Welfare, the Australian Bureau of Statistics, various Government agencies will be collating, taking away de-identified information and bringing it together to help us understand the lives of our people, our stories, not just in terms of what is happening to us in terms of accessing services, but what we might aspire for in terms of wanting to grow and get jobs, with education, understanding the barriers.

Dr Ben Gauntlett

- Because the linking of data can ensure that we make sure that no individual with disability is left behind.

Voiceover

- How it will work – the Council [Title screen]

Dr Ben Gauntlett

- The data asset is to be co-governed by governments and the disability community.
- The mechanisms of co-governance will be a Council made up of half government representatives and half disability community members, and a Charter will outline acceptable and unacceptable uses of the assets.
- The Council itself will be an advisory body that reports directly to disability ministers. And the role of the Council is to make sure the asset is used correctly and only for the purposes that align with community expectations

Voiceover

- How it will work – the Charter, privacy and security [Title screen]

Catherine McAlpine

- There needs to be strong protections in place to ensure that the data asset is not used against the wishes of people with disability. This includes having a Charter which will make sure the disability community knows how their data is being used, and are comfortable with how it is being used.

Dr Scott Avery

- There are safeguarding mechanisms and they are built into the charter to protect the privacy of individuals within the community.

Catherine McAlpine

- The draft rules make it really clear that the asset cannot be used to identify people or to make a decision about an individual's access to government funding. It cannot be used to support automatic decision-making tools when a computerised process helps or replaces a human decision-maker. This is very clear and is not the purpose of the asset.

Paul Hardcastle

- There is the legal protections, there's the disability community engagement, there's the oversight of the disability community in relation to these things.
- And there will be audits and a range of things to ensure people are using the asset in accordance with what ministers will agree to in the Charter.

Voiceover

- How it will work – ethical considerations and working with the disability community [Title screen]

Dr Scott Avery

- I think the ethics of inclusion, it is not just about what is in the data, but understanding who is not in the data, to make sure that when we are using this data asset, to make decisions that affect the lives of the disability community, we really need to push our understanding to make sure just who is in the room, but whose voices are not in the room and where making that decision.
- So the people who are making the decisions need to know the implications of that. And that's where I think the voice of disability is vital in the implementation.
- What does intersectionality mean? I'm going to talk about it in terms of, there are groups within the disability community that have different experiences to other groups.
- So it is recognising it's more than diversity. It's saying that people within the disability community have different experiences, particularly around discrimination.
- I come from the First Nations disability community, and in addition to some of the barriers that are disability related, what we might call ableism, First Nations people often experience racism as well. And these things come together and act as a barrier to their inclusion.
- So an example I have from our community, not far from where I am in Western Sydney, there is an Aboriginal man who I have spoken with and he has an intellectual disability and he says "when I go shopping, I get confronted by security guards and he says, they think he's drinking. They think he's intoxicated.
- And this is a case where you have the presentation of disability in public which is not well understood, coupled with the stereotypes around drinking, around Aboriginal people and drinking, to create this socially isolating experience for that.

- Let's make the cultural values of caring, sharing and respect the cultural values that drive the implementation of this asset, and it sets how we use, how we tell our stories, not just how we collect the data but how we tell our stories.

Paul Hardcastle

- It is essential we continue work with the disability community to make this asset one that works for everyone.
- We can actually deliver an asset that will improve the lives of people with disability.

Voiceover

- Thank you for watching. For more information visit: www.ndda.gov.au/ [Title card]