

Understanding Autism Prevalence

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Abstract

Reported autism prevalence has risen markedly over the last decade and is rapidly becoming an area of focus for many countries around the world. In Australia, the National Disability Insurance Scheme (NDIS, Scheme) is the primary means of government financial support available for people with disability.

NDIS participants with autism and developmental delay, which can often precede an autism diagnosis, account for 45% of all participants and 75% of participants under 18 years of age. Understanding why the largest cohort in the Scheme is rapidly increasing can provide insight to inform effective Scheme design.

This paper summarises key findings from recent research into international trends of autism prevalence and the proposed drivers of these increasing trends. The paper also includes quantitative analysis using the Person-Level Integrated Data Asset (PLIDA, formerly MADIP) from the Australian Bureau of Statistics to assess the potential impact of changing government financial incentives on autism prevalence in Australia using the roll out of the NDIS by age and region as a natural experiment.

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The views expressed in this paper are my own and do not necessarily reflect those of the National Disability Insurance Agency or the Sir Roland Wilson Foundation.

1 Introduction

Over the past two decades, society has experienced a significant shift in the ideology of disability. Across the world, societies are moving away from the institutional segregation of people with disability, towards integrating the needs of people with disability into their systems. Ultimately, society aims to recognise disability as a natural part of the human continuum, not separate from it, enabling people with disability to exercise their rights to the same extent as others. This is what Gerard Quinn, UN Special Rapporteur on the rights of persons with disabilities, refers to as the shift in systems of disability support away from a medical model towards a social model and onward to a human rights model (Quinn, 2022).

As the movement to recognise the rights of people with disability intensified, so did the rise in awareness of neurodiversity. Neurodiversity refers to the idea that “people experience and interact with the world around them in many different ways” and whilst it refers to the diversity of all people, it is often used to describe people with disabilities stemming from neurological or developmental conditions, the most prominent being that of autism (Baumer & Frueh, 2021).

Autism constitutes a spectrum of neurodevelopmental conditions collectively defined by specific behaviours and differences in social communication and learning (APA, 2013). Worldwide, the number of people being diagnosed with autism has been rising with a marked increase observed over the last decade (Zeidan et al., 2022; Solmi et al., 2022).

However, there is considerable controversy around the drivers of this trend. Some studies hypothesise that non-aetiological factors, such as broadening of diagnostic criteria, diagnostic switching from other developmental disabilities, increases in provider services, availability of government funding, and awareness of autistic spectrum disorders in both the lay and professional public, are the primary drivers of increases to reported prevalence. Others suggest additional factors including social awareness, behavioural incentives created by the way in which programs are funded as well as genetic and environmental factors linked to the aetiology of autism should also be considered.

In Australia, the rate of the rise in prevalence is steeper than other countries with comparable economies and health profiles, and coincides with the introduction of the National Disability Insurance Scheme (NDIS), a pioneering public policy initiative to provide individualised support for people with disability through a social disability framework. Despite being world-leading in concept, sustainability of this federal government program, partly arising from greater than expected number of participants with autism, alongside the continued systemic neglect of people with disability illuminated by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has resulted in calls for a systemic review of disability support in Australia.

This paper provides an overview of research in global autism prevalence, allowing us to understand the Australian experience in the context of international trends. It also discusses the key drivers of rising prevalence in autism and provides insights about the potential impact of the NDIS in Australia. Finally, the paper concludes with thoughts on implications for future disability policy reform.

2 Global Autism Prevalence

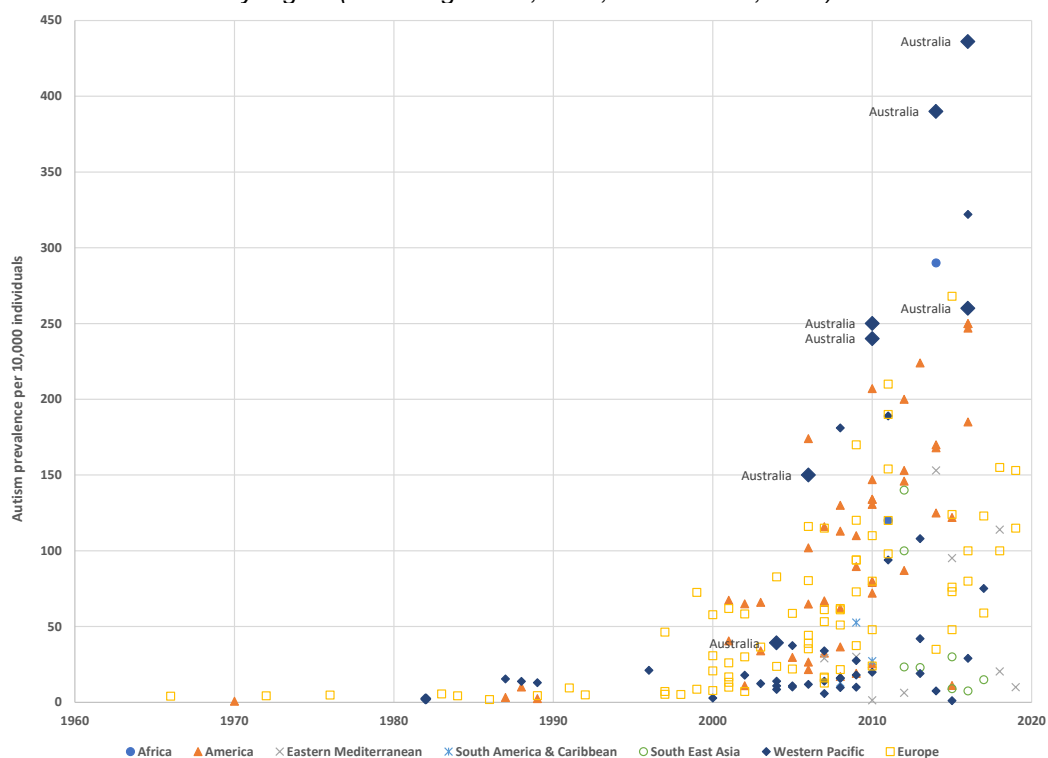
Studies of autism prevalence have established an increasing trend over the last fifty years, with a marked increase observed over the last decade. This trend is more pronounced in developed countries with higher socio-demographic index values. Estimates of prevalence in Australia are some of the highest in the world and have grown faster than the global average.

Evidence also suggests that whilst autism prevalence is higher in males, the gender ratio has been decreasing in countries with developed economies. Similarly, lower rates of autism prevalence in children facing social disadvantage or from culturally and linguistically diverse backgrounds have reversed and are now more likely to be diagnosed than their Caucasian and socially advantaged counterparts. These findings suggest a potential catch up in diagnosis in cohorts who were previously underdiagnosed.

Increasing Autism Prevalence

One of the first epidemiological studies of autism found that 4.5 of every 10,000 individuals in the UK displayed evidence of autistic behaviours (Lotter, 1966). Since then, many systematic reviews of epidemiological studies across the world have been conducted. In a cornerstone paper published in 2012, the median estimate of autism prevalence was between 60 and 70 people out of every 10,000 individuals (Elsabbagh et al., 2012). Most recent reviews which include several large-scale surveys, revise the median estimate to 100 people with autism out of every 10,000 individuals. Estimates of prevalence in Australia are some of the highest in the world (Zeidan et al., 2022; Salari et al., 2022).

Figure 1 Autism prevalence in a systematic review of studies from 1966 to 2022 by region (Elsabbagh et al., 2012; Zeidan et al., 2022)



United States of America

In the USA, the Autism and Developmental Disabilities Monitoring (ADDM) Network, established by the Centers for Disease Control and Prevention (CDC), collects data from eleven states¹ to better understand the number and characteristics of children with autism and other developmental disabilities. Estimates of autism prevalence in children aged 8 years has increased from 67 out of 100,000 individuals (1 in 250) in 2000 (CDC, 2014) to 276 out of 10,000 individuals (1 in 36) in 2020 (Maennar et al., 2023).

Canada

In Canada, the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) established by Canadian Institutes of Health Research, was used to study the prevalence of 5- to 14-year-olds in three provinces, covering almost a third of the country's population. Estimates of prevalence have increased from 37 out of 10,000 individuals (1 in 270) in 2003 to 159 out of 10,000 individuals (1 in 63) in 2015 (Ofner et al., 2018). The most recent Canadian Health Survey in 2019 now estimates that 200 out of 10,000 children aged 1 to 17 years (1 in 50) are diagnosed with autism (PHAC, 2022).

United Kingdom

In the United Kingdom (UK), a 2018 national study using the primary health care database estimated prevalence at 78 people out of 10,000 individuals across all ages (O'Nions et al., 2023). In 2021, the National Autistic Society estimated autism prevalence at 100 people out of 10,000 individuals (1 in 100). Prevalence in children is higher, with a study using the UK Pupil Census Data estimating prevalence in 5- to 19-year-olds at 176 people out of 10,000 cases (1 in 57) (Roman-Urrestarazu A. et al., 2021). Whereas estimates of prevalence for the older population is markedly lower but also increasing. The Office for National Statistics (ONS), which reports on outcomes for people with disability aged between 16 and 64 years and in employment, introduced autism as a separate disability in January 2020 and reported an increase in prevalence from 33 people out of 10,000 individuals in June 2020 to 55 people out of 10,000 individuals in June 2021 (ONS, 2023).

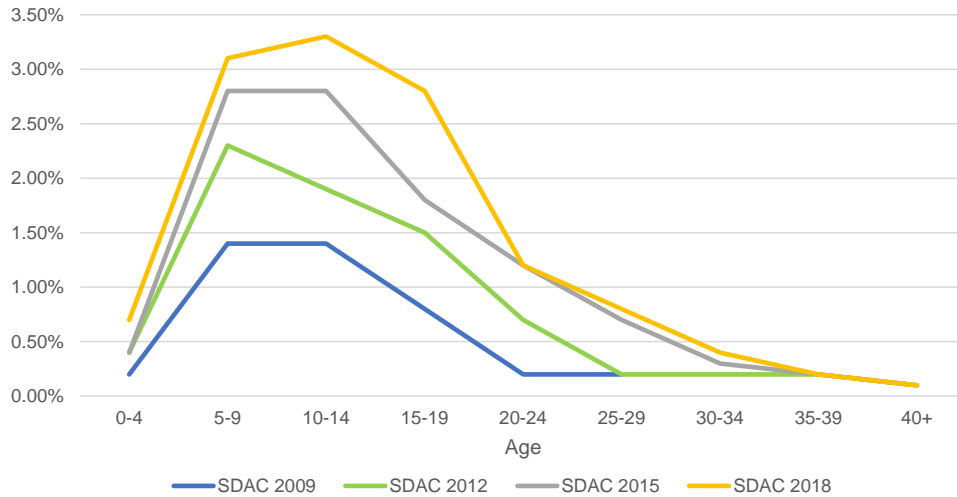
Australia

In Australia, national data collected in the Survey of Disability, Ageing and Carers (SDAC) by the Australian Bureau of Statistics (ABS) estimated autism prevalence at 83 people out of 10,000 individuals in 2018, an almost threefold increase from the estimate of 30 people out of 10,000 individuals in 2009 (ABS, 2009; ABS, 2019). Figure 2 shows the increasing trend of autism prevalence estimates from the last four surveys by age group. However, peak bodies in the Australian disability sector estimate true prevalence to be higher at 143 cases out of 10,000 individuals (1 in 70) based on updated studies in Australia and other countries with comparable economies and health profiles (Aspect, 2018). Research using the Longitudinal Study of Australian Children (LSAC) tracks autism prevalence in two cohorts of children born in 1999-2000 and 2004-2005. The researchers found that prevalence was higher in the younger cohort and increased over time for both cohorts with a prevalence of

¹ The states include Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin.

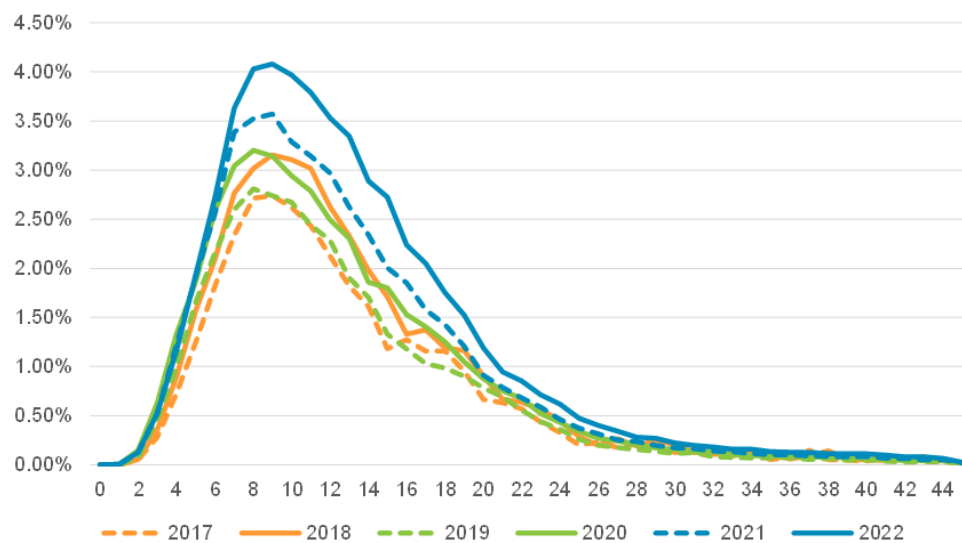
436 people out of 10,000 individuals (1 in 23) in the younger cohort and 260 people out of 10,000 individuals (1 in 42) in the older cohort by age twelve (Randall et al., 2016; May et al., 2017; May et al., 2020).

Figure 2 Autism prevalence by age group in Australia (ABS, 2019)



Analysis of NDIS participation rates also shows rising rates of prevalence, year on year. Figure 3 shows the proportion of the Australian population that is participating in the NDIS with a primary disability of autism. These rates reflect a subset of the Australian population with autism, that is those with significant disability, and do not include people with multiple disabilities including autism, where autism is not their primary disability. As such, the rates shown below, while in line with estimates from the SDAC survey, are an underestimate of true prevalence in Australia.

Figure 3 NDIS participation rates for people with autism by age in Australia (NDIA, 2023)



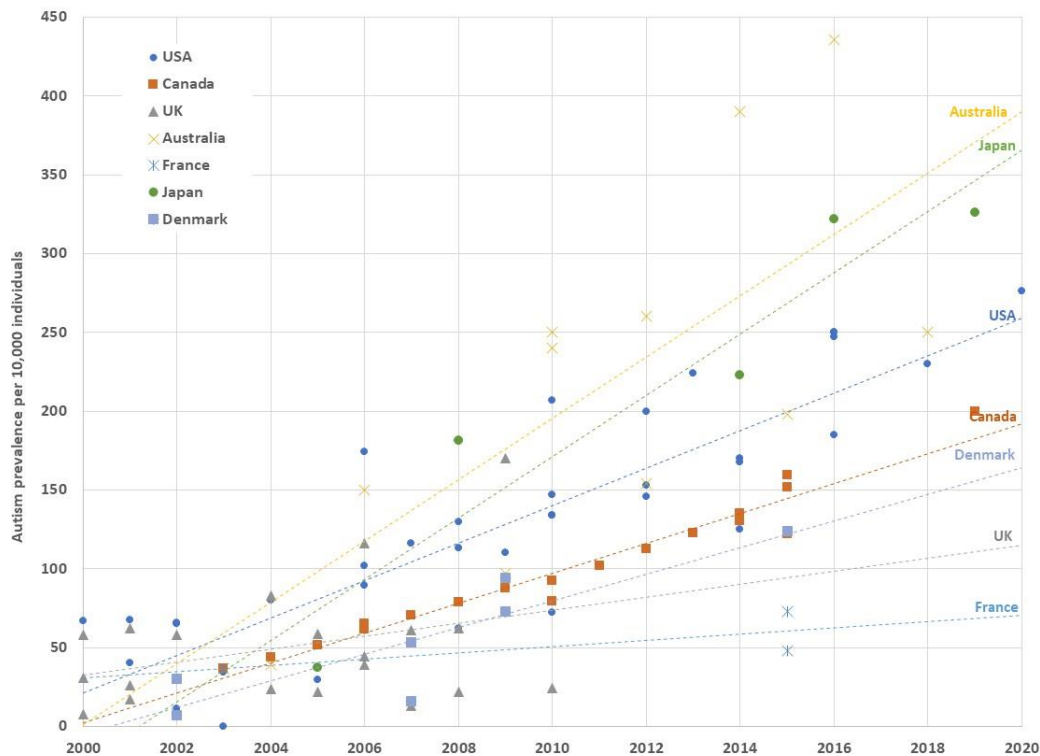
Prevalence in Children

Estimates of autism prevalence in various studies of children are compared across selected countries with the highest socio-demographic index. The growth in estimates of autism prevalence in children is steeper in Australia than growth in other countries, including the

USA, Canada and the UK, and is similar to that in Japan, where a community-oriented system of early detection and early intervention has been in place since the 1990's (Honda, 2002; Sasayama et al., 2021).

Figure 4 shows prevalence estimates from longitudinal and cohort studies over the last two decades with the trend line reflecting the line of best fit for each country. The Australian estimates above the trend line are from longitudinal studies using the LSAC database, whereas the estimates below the trendline are from national survey data, which peak bodies believe underestimate true prevalence. This suggests growth in prevalence in Australia could be steeper than that observed in Japan.

Figure 4 Autism prevalence in studies of children from 2000 to 2022 by country



Decreasing Gender Ratios

Gender, specifically being male, is a well-established genetic factor associated with increased likelihood of an autism diagnosis. Studies in developed countries report that the prevalence of autism in boys is more than four times higher than in girls (May et al., 2020; Zeidan et al., 2022; Maennar, 2023). Potential reasons for the difference in gender-based prevalence rates point to socio-cultural differences in the perception of acceptable behaviours for girls and boys impacting the detection and diagnosis of autism in girls (Dworzynski, 2012; Hiller, 2016; Geelhand, 2019). As such, studies have shown that a greater proportion of females with autism are also diagnosed with intellectual disability and are impacted by their disability to a greater extent than males (Brugha et al., 2016; Baio et al., 2018; Delobel-Ayoub et al., 2019).

Figure 5 shows the ratios of males to females with autism identified in 162 studies by geographic region in a systematic review by Elsabbagh et al. (2012) and in an update by

Zeidan et al. (2022). Despite variation in study sample size and geographical coverage, median ratio of males to females has remained stable from a decade ago.

Figure 5 Gender ratios in a systematic review of studies from 1966 to 2022 by region (Elsabbagh et al., 2012; Zeidan et al., 2022)

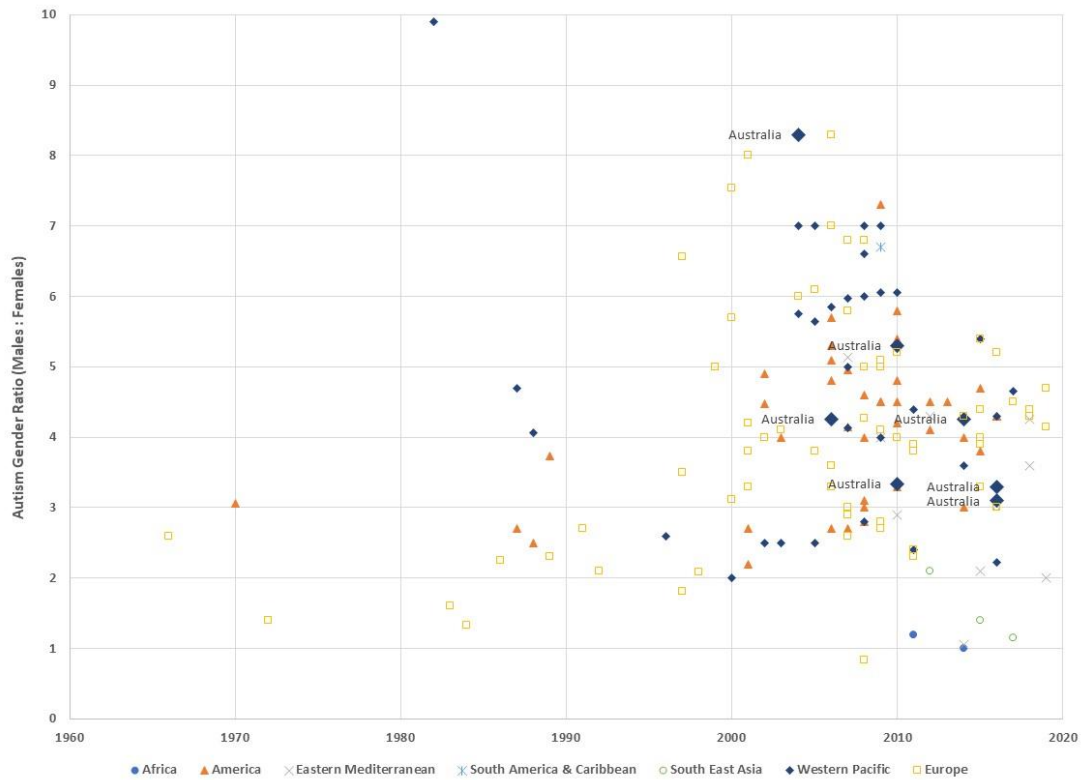
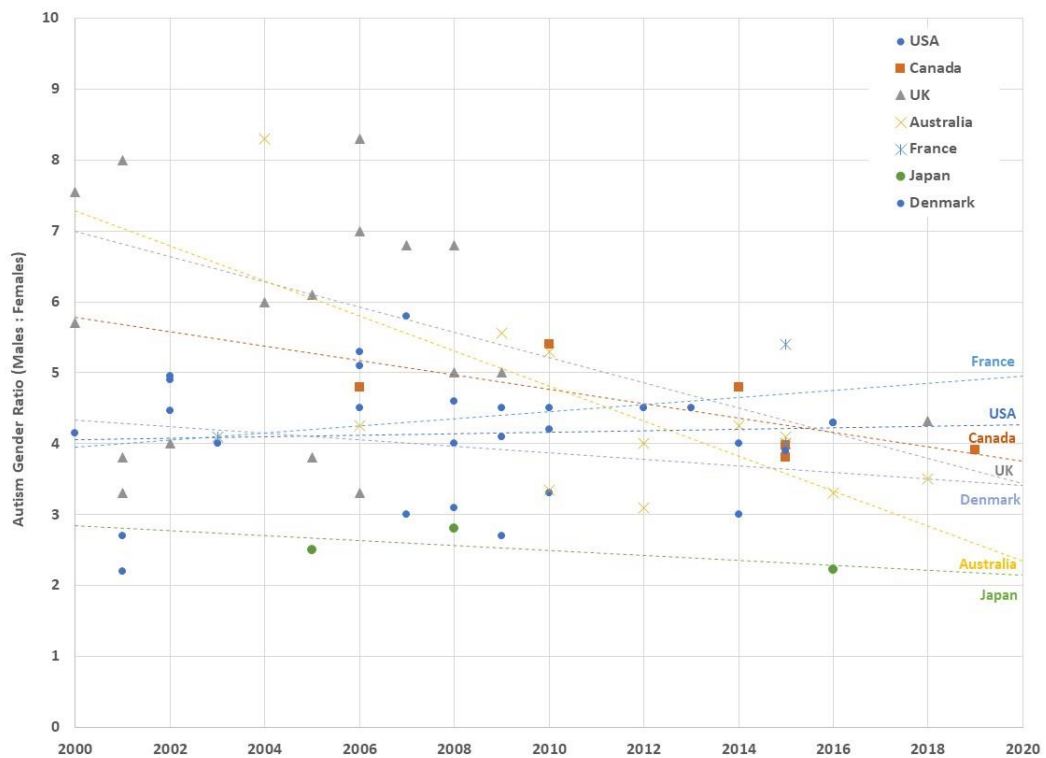


Figure 6 Gender ratios in autism prevalence studies on children from 2000 to 2022 by country



However, gender ratios have been decreasing for countries with higher socio-demographic index. Figure 6 shows the gender ratio for studies on children in selected countries over the past two decades. Whilst the ratio remains stable in the USA and France, the ratio is decreasing for Australia, Canada and other European countries. In Australia, recent estimates of the gender ratio suggest it could be as low as 3.1 to 3.5 (SDAC, 2019; May et al., 2020).

Socioeconomic and Racial Disparity

Studies have also proposed an association between autism and sociodemographic and socioeconomic factors. Earlier studies found limited evidence of the association between autism and social disadvantage once diagnostic methods and service availability were taken into account (Rai et al., 2012; Delobel-Ayoub et al., 2015; Durkin et al., 2017).

However, recent studies show that children facing social disadvantage were more likely to receive an autism diagnosis (Christensen et al., 2019; Maenner, 2020; Roman-Urrestarazu A. et al., 2021). Further, these studies also considered the interaction between social disadvantage and race, finding that children from culturally and linguistically diverse backgrounds were more likely to receive an autism diagnosis (Abdullahi et al., 2018; Christensen et al., 2019; Maenner, 2020; Roman-Urrestarazu A. et al., 2021).

In Australia, children facing greater socioeconomic disadvantage are more likely to receive an autism diagnosis (Nielsen et al., 2023). On the other hand, the evidence around the association between race and autism is not as clear. An earlier study using Western Australian data found that children born to indigenous mothers were half as likely to receive an autism diagnosis than children born to Caucasian mothers, attributing this to low diagnostic and support service availability in remote areas, where many indigenous communities reside (Fairthorne et al., 2017). The study also found lower rates of autism in children born to migrant mothers from Asia, who were typically of a higher-than-average socioeconomic status. However, more recent studies have found that children born to mothers from non-English speaking backgrounds, particularly those from East Africa, were more likely to receive an autism diagnosis (Abdullahi et al., 2019; Huang et al., 2021; Abdullahi et al., 2023).

A similar relationship between race and autism prevalence was also observed in the USA. In the 2023 CDC report, children from Black, Hispanic, Asian or Pacific Islander backgrounds reported higher autism prevalence than children from Caucasian backgrounds, whereas in 2010, non-Hispanic Caucasian children were 2.5 times more likely to be diagnosed with autism than non-Hispanic Black children (Zeidan et al., 2022; Maennar, 2023).

Researchers suggest these racial disparities result from a catch up in diagnosis in minority groups who were previously underdiagnosed (Christensen et al., 2019; Maenner, 2020; Roman-Urrestarazu A. et al., 2021).

3 Drivers of Rising Prevalence

Whilst there is consensus over the increasing trend of autism prevalence worldwide, there is considerable controversy as to what is driving this trend. Autism prevalence research predominantly points to non-aetiological factors as the primary drivers of reported prevalence. Elsabbagh et al. (2012) state that a “broadening of the diagnostic concepts, diagnostic switching from other developmental disabilities, service availability, and awareness of autistic spectrum disorders in both the lay and professional public” account for most of the increase in reported prevalence. These drivers are also identified in other systematic reviews (Lai et al., 2014; Baxter et al., 2015; Chiarotti and Venerosi, 2020; Zeidan et al., 2022) as well as large scale studies of autism prevalence in developed countries (King and Bearman, 2009; Hansen et al., 2015; Ward et al., 2016; Baio et al., 2018; Maennar et al., 2020; May et al., 2020).

A systematic study investigating the drivers of prevalence attributed almost half of the variability in prevalence estimates to factors such as case definition, varying procedures to diagnose autism and geographical area (Chiarotti and Venerosi, 2020). Additional factors including social awareness, behavioural incentives through funding as well as genetic and environmental factors linked to the aetiology of autism should also be considered (Hertz-Picciotto et al., 2009; Elsabbagh, 2012; Grabrucker et al., 2013; Ng et al., 2017; Kim et al., 2019; Chiarotti and Venerosi, 2020; Fombonne, 2020; Zeidan et al., 2022).

With the rise in autism prevalence being steeper in Australia than other countries with comparable economic and health systems, it is plausible that the growth of prevalence rates above the global average in Australia can be attributed to the financial incentives created by government policy, specifically the implementation of the NDIS.

Changing Diagnostic Criteria

One stream of research studies the impact of the changing criteria of developmental assessments on the epidemiological estimates of autism prevalence. Studies show that the introduction of new criteria in the 1990’s, specifically the fourth edition of the Diagnostic Statistics Manual of Mental Disorders (DSM-IV) and the International Statistical Classification of diseases and related health problems (ICD-10), were associated with higher case-finding rates than earlier editions of the criteria² (Hertz-Picciotto and Delwiche, 2009; Keyes et al., 2012; Baxter et al., 2015; Hansen et al., 2016). Conditions like Asperger’s syndrome were being included as part of spectrum of autism. On the other hand, studies show that the introduction of new criteria in the 5th edition of the Diagnostic Statistics Manual of Mental Disorders (DSM-5) in 2013, resulted in decreases or at most no change in the number diagnosis (Kim et al., 2014; Maennar et al., 2014; Bent et al., 2017; Kulage et al., 2020; Peters & Matson, 2020). This suggests that other factors are contributing to the increases in autism prevalence over the last decade³.

² Earlier criteria include DSM-III, DSM-III-R and ICD-9.

³ ICD-11 guidelines were published in 2018 and came into effect on 1 January 2022. The impact of the changes in ICD-11 on autism prevalence has yet to emerge.

Diagnostic Substitution

Another stream of research, highlighting the intersection of intellectual disability and autism, points to diagnostic substitution (or switching to a different diagnosis) as a driver of increasing prevalence (Elsabbagh et al., 2012; May et al., 2017; Dunn et al., 2019). The inclusion of conditions with milder impacts in the expanded criteria of DSM-IV has increased the identification of people with autism who have less intense or constant support needs and who may have previously received a diagnosis of intellectual disability (Dunn et al., 2019). Diagnostic substitution also occurs when some diagnostic categories become increasingly familiar to health professionals (Elsabbagh et al., 2012).

Increasing Awareness

Studies have also attributed increasing prevalence to the heightened awareness of autism in both the lay and professional public (Prior, 2003; Elsabbagh et al., 2012). Prior (2003) noted that public and professional awareness of autism had increased markedly over time, and the possibility of the existence of an autistic condition is considered much more frequently in children with disabilities of unclear origin and of a perplexing nature. More recent research observed a positive association between autism prevalence and educational attainment, indicating a potential under-diagnosis amongst those in the lowest education attainment categories (Durkin, 2017). Others suggest that the increased awareness of autism in society and the media have resulted in increased diagnosis of those who were previously under-diagnosed, particularly in females and the older population (May et al., 2018, Gibbs et al., 2019; Meguid et al., 2021).

Genetic and Environmental Factors

Changes in genetic and environmental factors relating to the aetiology of autism have also been cited as potential explanations for increases in autism prevalence. Evidence from twin studies suggests that autism is linked to an individual's genetics; however, the exact genetic causes of autism remain unknown (Steffenburg et al., 1989; Ritvo et al., 1991; Bailey et al., 1995; Hallmayer et al., 2011; Kim et al., 2019).

Studies have investigated the impact of genetic biomarkers and environmental exposures on the corresponding likelihood of being diagnosed with autism. Of the many factors tested, those relating to gender, parents' mathematical aptitude, mothers' advanced age and mothers' psychiatric conditions as well as her use of psychiatric drugs and agents to modulate immune systems during pregnancy had convincing associations with increased diagnosis of autism (Baron-Cohen et al., 2012; Howsmon et al., 2017; Grubucker et al., 2013; Ng et al., 2017; Kim et al., 2019).

Availability of Government Supports

Studies have surmised that the availability of government-funded services and supports which require a diagnosis could be another driver of increasing autism prevalence (Nassar, 2009; Randall et al., 2015; Bent et al., 2017; Taylor et al., 2017). Researchers suggest that some of the increase could relate to diagnostic substitution from conditions with overlapping

symptoms (for example, ADHD, or specific learning disorders such as dyslexia) to autism by health professionals, so that patients can access basic services (Elsabbagh et al., 2012; May et al., 2017; Taylor et al., 2017).

In Australia, the NDIS is now the primary source of funding for people living with a disability. Prior to its introduction, Australians accessed disability supports either privately or from providers who were block funded by state and territory governments and from some federal funded programs like Helping Children with Autism (HCWA), which provided early intervention funding of up to a total of \$12,000 to eligible children (under 6 years of age with a diagnosis of autism) to be used before the child turned 7.

Pre-NDIS Programs in Australia

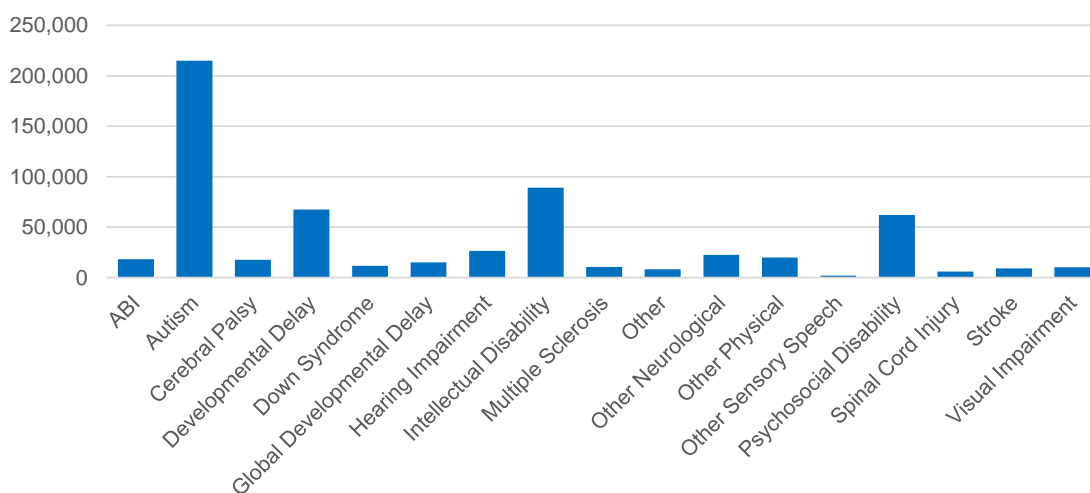
Prevalence research using data about pre-NDIS programs in Western Australia and HCWA found associations between eligibility for government programs and prevalence, with clear spikes in the frequency distribution of age at diagnosis just before the end of the eligibility period for funding (Nassar et al., 2009; Randall et al., 2015; Bent et al., 2015).

Randall et al. (2015) point to the Helping Children with Autism (HCWA) program as potentially contributing to the observed difference in prevalence between the younger and older cohorts in the LSAC study. Children in the younger cohort were under six when the HCWA funding became available, but children in the older cohort were not eligible for the funding.

NDIS

Despite observing marked increases in autism prevalence over the last decade in Australia, coinciding with the introduction of the NDIS, there has been little research that evaluates the national impact of this policy on the prevalence of autism. The NDIS now supports more than 610,000 individuals as of 30 June 2023, of which almost 215,000 participants had a primary diagnosis of autism, accounting for 35% of the total Scheme population. Participants with autism received \$33,800 of supports on average over the twelve months to 30 June 2023 (NDIA, 2023).

Figure 7 Participants in the NDIS by Primary Disability at 30 June 2023 (NDIA, 2023)



The NDIS was rolled out in a staggered manner across various regions for selected age groups between 1 July 2013 and 1 July 2020⁴. The phasing schedule was obtained from the NDIS trial and transition bilateral agreements between State or Territory and Commonwealth governments⁵.

This variation in policy implementation creates an opportunity to compare prevalence trends for cohorts that are eligible and ineligible for the NDIS. Analysis of cross cohort prevalence allows inference about the potential impact of the NDIS on autism diagnoses.

This analysis relies on data from the Person-Level Integrated Data Asset (PLIDA, formerly MADIP), which combines administrative records from various government departments, including the Department of Health and the National Disability Insurance Agency (NDIA), and is representative of the Australian population.

To estimate autism prevalence, population data by region and age is obtained from historical Census datasets and individuals with a confirmed autism diagnosis are identified in the data if they:

- have accessed items⁶ from the Medicare Benefits Schedule (MBS) to confirm the diagnosis of a complex neurodevelopmental disorder or disability; or
- have accessed any of the MBS items⁷ related to subsequent services which require a confirmed diagnosis; or
- are an NDIS participant with a primary⁸ disability of autism.

The analysis focuses on prevalence in the population aged between 0 and 14 years to reflect the age limit on MBS claims for the specified codes⁹. The analysis also covers the period from 2011 to 2021, noting that the NDIS roll out begins in 2013 and the MBS dataset is a snapshot of claims in each period.

There are two limitations to this analysis. Firstly, historical prevalence prior to 2011 is not captured in the data, so the analysis looks at additional prevalence between 2011 and 2021. Whilst some of the historical prevalence may be captured as individuals become eligible for the NDIS, their date of diagnosis is not recorded, and they will be allocated to the period in which they became eligible for the NDIS. This may artificially increase the rates of autism in later periods but is unlikely to have a material impact, given the small magnitude of recorded prevalence prior to 2011 (SDAC, 2009).

Secondly, the MBS codes cover all complex neurodevelopmental disorders and disabilities, not just autism. A cross match between those who were identified in both the MBS and NDIS

⁴ The Scheme was available in most regions by 1 October 2018 and throughout Australia by 1 July 2019 (noting, availability in Christmas Island and the Cocos Islands began on 1 July 2020).

⁵ <https://www.ndis.gov.au/about-us/governance/intergovernmental-agreements#ndis-trial-and-transition-agreements>

⁶ The item numbers are 135 (or equivalent telehealth item 92141) or 289 (or equivalent telehealth item 92434).

⁷ The item numbers are 82015, 82020, 82025 or 82035 (or equivalent telehealth items 93035, 93043, 93036 or 93044).

⁸ Secondary disability and multiple conditions are not recorded in the data.

⁹ From 1 March 2023, patient eligibility for the relevant codes expanded, from under 13 years of age to under 25 years of age.

datasets showed that 84% of the sample had a primary disability of autism, 8% had developmental delay and a further 6% had intellectual disability. By including all complex neurodevelopmental disorders and disabilities using the MBS data, this analysis is likely to capture a proportion of the individuals who may have co-occurring autism but a different primary disability. Developmental delay is often a precursor to a later autism diagnosis and intellectual disability is also common co-occurring condition with autism.

Figure 8 shows the cumulative and incremental rates of autism in Australians aged between 0 and 14 years. The two cohorts reflect the population in regions where the NDIS was available and where the Scheme was yet to roll out. Individuals with autism are identified using both the MBS and NDIS datasets. Faster growth can be observed in regions where the NDIS has rolled out, but the pace of growth has slowed since 2019 when the Scheme became available throughout the country. Increases in incremental rates prior to 2019 suggest that the roll out of the NDIS has had an impact on the number of people seeking a diagnosis.

Figure 9 shows the autism rates for the same cohorts using only the MBS dataset to identify individuals with autism. In this case, growth in autism rates remains similar between the two cohorts and the pace of growth once again slows after 2019. Incremental rates remain stable prior to 2019, in contrast to the clear increases observed in Figure 8. This could reflect the delayed allocation of individuals with diagnoses obtained prior to 2011 as well as individuals seeking diagnoses from private practitioners.

Figure 8 Cumulative (left) and incremental (right) autism rates in Australia for people aged 0 to 14 years by Availability of the NDIS

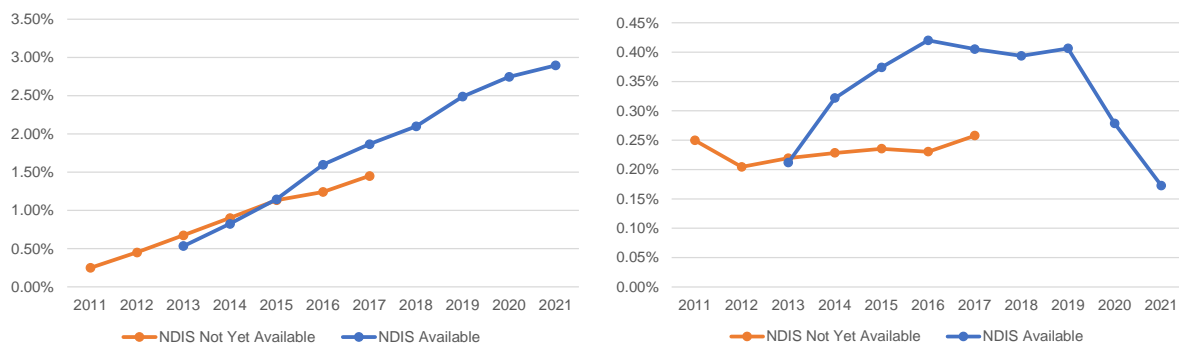
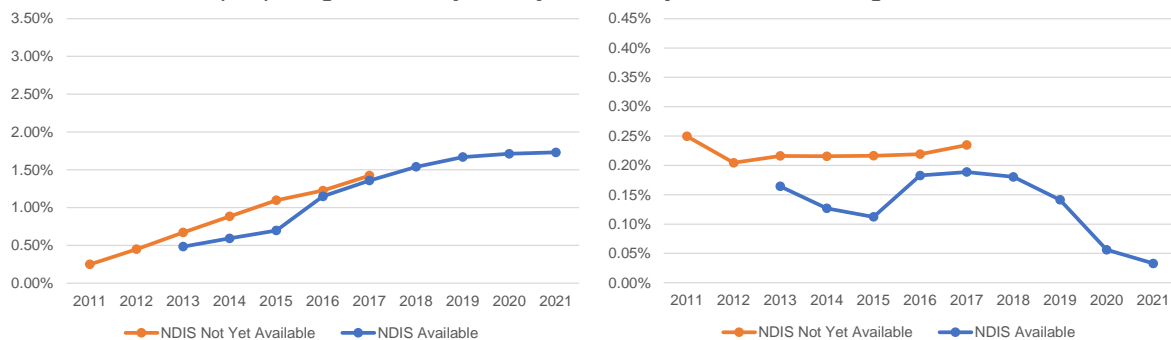


Figure 9 Cumulative (left) and incremental (right) autism rates in Australia for people aged 0 to 14 years by availability of the NDIS using MBS data



4 Considerations for Public Policy Reform

Another stage of disability reform has begun in Australia. Multiple pressures relating to the sustainability of costs and the efficiency of markets since the introduction of the federally funded NDIS 10 years ago, has required an independent review of the NDIS, the findings of which were submitted to the government at the end of October 2023 but have not yet been made public. Earlier in October 2023, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability handed down a comprehensive list to 222 recommendations, to address the systemic neglect as well as the discrimination and exclusion experienced by people with disability in Australia.

Implications of the key findings in this paper for future reform are discussed below.

Neurodiversity is no longer rare.

Currently, across all ages, 1 in 70 Australians identify as being a person with autism. More than 1 in 25 children aged eight are receiving an autism diagnosis, noting that diagnoses last a lifetime. More broadly, the 2022 Australian Early Development Census found that 22% of children (1 in 4.5) have been assessed as developmentally “vulnerable”.

As the population ages, the shape of the prevalence distribution will change to reflect the growing proportion of the younger population who identify as being neurodiverse, including those with a formal diagnosis of autism. Significant variation in neural function is no longer what was historically referred to as “atypical development” and needs to be recognised as a natural part of human diversity.

Further increases in autism prevalence may arise from the catch up in diagnoses in groups that were previously underdiagnosed. These include females, older people and those from cultural and linguistically diverse backgrounds.

Institutional change should reflect this demographic shift.

Calls for an inclusive system of mainstream and community support for people with disability have escalated. Despite government spending more per capita on disability support than most OECD countries, a meaningful shift in the institutional architecture of disability support has yet to occur.

There are several separate government strategies, initiatives and reforms currently underway, all with a view to better support people with autism and disability at each stage of life – the National Autism Strategy, the National Early Childhood Strategy, the National Early Childhood Program, state-wide reforms for inclusive education and curriculum, the NDIS Review, government response to the Disability Royal Commission, to mention a few.

Effective and meaningful transformation of the disability support systems, especially across key reform areas such as access to services, healthcare, education and employment, is now more important, given the changing composition of our population, where neurodiversity and autism are no longer outliers, but a major part of the normal curve.

NDIS reform should be considered within wider disability system reform.

The NDIS was designed on the principles of insurance, where the economic cost of significant and substantial disability is insured by the government, who will fund reasonable and necessary supports to lead an ordinary life. Participants needing a lifetime of support can access funding via the permanent disability stream, whereas participants who may benefit from early intervention, typically those with a lower level of need, can receive funding for early intervention supports.

The NDIS faces significant pressure to address rising costs and increasing demand arising from higher-than-expected numbers of children accessing the Scheme, fewer than expected participants leaving the Scheme after early intervention and a rapidly growing proportion of participants with autism (NDIA, 2023).

Australian estimates of prevalence in children are the highest in the world and have grown faster than the global average. Incentives in government policy, specifically the NDIS, is the key factor unique to the Australian context and potentially explains the additional growth in Australian prevalence. Further work is needed to identify the causal effect of the NDIS on autism prevalence, leveraging the roll out of the NDIS by region and age group as a natural experiment.

Nevertheless, reforms to the NDIS design should consider the insurability of “high frequency” events, in this case conditions with high rates of incidence, as well as the investment needed to ensure support for people with autism can be accessed in safe and inclusive settings.

Further acceptance of disability in society is needed.

“Children of scientists and engineers (and those with acute technical aptitude) may inherit genes that not only confer intellectual talents but also predispose them to autism” (Baron-Cohen, 2012).

Tech-savvy communities like Silicon Valley in the US and Eindhoven in Netherlands have reported high rates of autism and are beginning to embrace their neural diversity. As actuaries, we are possibly only two degrees of separation from someone living with, or caring for, a person with autism. A shift in public awareness and acceptance of disability is already underway but further changes in societal attitudes are needed, so that widespread acceptance of human diversity in ability can become a reality. This would perhaps lead to world where a large part of the autism spectrum is not a disability at all under the social model of disability.

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