

# Exploring Inequity in Childhood Neurodisability in a Disadvantaged Metropolitan Region in Australia

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## Research

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# Abstract

## Background

South Western Sydney (SWS) region, in the state of New South Wales (NSW) in Australia is a culturally and linguistically diverse area of marked social disadvantage. Using the best available data sources, we aimed to explore the prevalence of children with developmental disability and their access to disability and special education support services, to identify equity gaps.

## Methods

Data on the potential number of children in SWS with neurodisability was identified from the district wide Child Developmental Assessment Service (CDAS) database of public-funded Community Paediatrics services, the NSW/Australian capital territory (ACT) Cerebral Palsy (CP) register, the State-wide Infant Screening-Hearing (SWISH) Program, the Royal Institute for Deaf and Blind Children and the Department of Education. The proportion of children with access to disability services for children up-to 18 years of age was explored from the datasets of the National Disability Insurance Scheme (NDIS). Relative risks were calculated to compare any differences in proportion of supports in SWS compared to NSW.

## Results

In 2018, 503 children (median age 4.3 years) were assessed by CDAS; 65% had autism spectrum disorder (ASD) either alone or in association with global developmental delays and 24% had global developmental delay. The prevalence of CP in SWS was 1.86/1000; with a higher proportion of severe functional and intellectual impairment in SWS compared to the state. The prevalence of sensori-neural hearing loss in SWS was 2.2/1000, and more children in SWS had severe visual impairment compared to the state ( $P=0.003$ ). Students in support classes with special needs were overrepresented in SWS compared to the state ( $P<0.0001$ ). There were slightly more children with intellectual disability in SWS supported by the NDIS, but proportions for other conditions were comparable to NSW.

## Conclusions

While available data sources are incomplete, we identified greater proportions of children with neurodisability, experiencing more functional impairment in SWS, compared to NSW; with ASD being the most common neurodisability presenting to developmental clinics. We also identified potential equity gaps in disability service provision. A state-wide child disability register would aid planning and research, with concerted advocacy needed to improve equity in disability support provision in this region.

## Introduction

Childhood developmental disability is a clinical and public health concern globally, with profound impacts on children, families, the education system, and the health care system.<sup>1</sup> In recent years, there has been a shift in the epidemiology of children from predominantly physical disabilities to increasing emotional, behavioural and neurological disabilities.<sup>2,3</sup> Although globally child mortality has decreased, the years lived for children with a disability has increased since 1990.<sup>2</sup> Vision loss was the most prevalent disability, followed by hearing loss, intellectual disability, and autism spectrum disorder (ASD); however, intellectual disability was the largest contributor to years lived with a disability globally.<sup>2</sup> The rates for cerebral palsy (CP) in Australia are an exception to that trend, declining from 2.1/1000 live births (birth years 1995–1997) to 1.4/1000 live births (birth years 2010–2012).<sup>4</sup> Children with CP in Australia are more likely to reach adulthood than in previous decades, highlighting the need for evaluation and continuity of health and support services over the life course.<sup>5</sup>

Childhood-onset disability is common, with documented increases in prevalence in recent decades in the developed world,<sup>6</sup> but there is wide variation in what is measured and how it is measured, making comparisons between regions and countries difficult. A high proportion of ambulatory clinical work presenting to paediatricians in Australia is comprised of neurodevelopmental conditions and learning difficulties.<sup>7</sup> Childhood developmental disability is just under 10%, based on the survey data from the United Kingdom,<sup>8</sup> United States,<sup>6</sup> and Australia.<sup>9</sup> There are complexities in estimating the prevalence of developmental disability as the diagnostic criteria for ASD and other childhood disabilities have changed with the Diagnostic and Statistical Manual-5 released in 2013,<sup>10</sup> and the International Classification of Disease 11 in 2018.<sup>11</sup> National data on disability in Australia from 2012 and subsequently from

2018 by the Australian Bureau of Statistics (ABS) noted that the children with intellectual impairments, and sensory and speech disorders, as the most common reasons for children with disabilities. This survey, however, did not highlight specific practical diagnostic formulations that are often used by clinicians and did not address in adequate detail whether appropriate supports were available to these children and families.<sup>12</sup>

Robust measurements of the prevalence of childhood disability are critical to understanding the relationship between socio-cultural influences and child disability, and to aid service planning. There is strong evidence globally that childhood disabling conditions are often associated with, or exacerbated by social disadvantage.<sup>8 13 14</sup> Accurate disability data are also necessary for advocating for appropriate disability supports and educational placements according to their need. In Australia, the National Disability Insurance Scheme (NDIS) was established as a pioneering service to provide all eligible individuals with a significant disability, with autonomy and control over interventions and disability supports through registered service providers to maximise their function.<sup>15</sup> There are, however, several bottlenecks in service delivery and there are concerns for timely access to meet the needs of children and adults with disability from vulnerable backgrounds.<sup>16–20, 21</sup> Much of the critiques of the NDIS are related to service planning deficits, with a lack of accurate disability data to inform NDIS service provision to those most in need.

South Western Sydney (SWS) Local Health District is one of the eight metropolitan local health districts in the state of New South Wales (NSW), Australia, and a priority area for health service planning. It has the highest rate of population growth in NSW.<sup>22</sup> This region encompasses some of the lowest socioeconomic populations in NSW, large culturally and linguistically diverse groups, and a small but significantly disadvantaged Aboriginal and Torres Strait Islander population.<sup>23</sup> The region also has the highest rates of refugee settlement in NSW,<sup>24</sup> a population group reported to have an increased prevalence of childhood disability.<sup>25 26</sup>

Acknowledging the wide variation in terminology pertaining to child disability, we focused on children with neurodisability and aimed to arrive at an estimate of children living with disability in SWS using the best available data sources. We also aimed to explore access to disability support services through the NDIS and Department of Education - acknowledging increased rates of severe/profound disability in identified population groups, such as newly arriving refugees, and highlight equity gaps in this urban disadvantaged setting.

## Methods

### Data sources

We focussed on the available data for the number and proportion of children with neurodisability in SWS and we identified this data from a variety of available data sources. These included: the SWS district-wide Child Developmental Assessment Service (CDAS) database of the public funded Community Paediatric services; the NSW/Australian Capital Territory (ACT) CP Register; the State-wide Infant Screening-Hearing (SWISH) Program; data on visual impairment (VI) from the Royal Institute of Deaf and Blind Children (RIDBC); and NSW Department of Education data on students attending support classes for childhood disability. Data on the number of NDIS participants for children up to 18 years of age who were accessing services up to the quarter of July to September 2020 for ASD, Global Developmental Delay (GDD), CP, Intellectual Disability, and sensory impairments including hearing and visual impairment was extracted from the publically available website.<sup>27</sup> The data on access to services through NDIS was calculated up to September 2020 (as there is a general lag in accessing services once a child is identified with significant needs) whilst all other data sets were for 2018.

Further details of these datasets is presented in Supplementary file.

### Ethics

Ethics approval was obtained through the SWS Local Health District Human Research Ethics Committee (LNR/18/LPOOL/80). Additional ethical approval was granted for the use of the NSW/ACT CP Register data by the Cerebral Palsy Alliance Human Research Ethics Committee (approval 20180701).

### Data analysis

The proportion of children with disability in SWS was compared to rest of the state by performing simple descriptive statistics and chi-squared statistics. Population denominator data for population figures of children in NSW and SWS were derived from

HealthStats NSW (<http://www.healthstats.nsw.gov.au/>, accessed on 31 August 2021) for calculating Relative Risk (RR) for the proportion of children with disability in SWS compared to rest of the state and for access to NDIS services for SWS compared to NSW.<sup>28</sup> Data management and analysis was conducted using Stata,<sup>29</sup> SPSS<sup>30</sup> and Microsoft Excel. A p-value of < 0.05 was considered significant.

## Results

In 2018, there were 283,553 children aged below 18 years in SWS, constituting 14.4% of NSW population.<sup>28</sup>

**CDAS Database:** In 2018, there was complete data available on 503 children who attended CDAS clinics in SWS. The median age of children was 4.3 years, with 73% of children aged below five years (inter-quartile range (IQR): 3.5–5.1 years); 79% were male; 60% were from a culturally and linguistically diverse (CALD) background, and 6% were Aboriginal and Torres Strait Islander children. The three major diagnostic groups seen at the CDAS clinics were ASD (30%), GDD (24%) and ASD and GDD combined (35%) (Table 1). Children from a CALD background had a 21% increased risk of having GDD or ASD and GDD combined compared to non-CALD background children (RR = 1.21; 95% CI: 1.03–1.41).

Table 1  
Developmental diagnoses of children seen at CDAS, South Western Sydney, 2018

| Diagnosis  | No. of Children | Percentage |
|--|-----------------|------------|
| ASD  | 153             | 30%        |
| ASD&GDD  | 175             | 35%        |
| GDD  | 119             | 24%        |
| Specific Language Impairment   | 11              | 2%         |
| Normal/Low average development   | 18              | 4%         |
| Missing  | 27              | 5%         |
| Total  | 503             | 100%       |
| Note: CDAS: Child Developmental Assessment Service, ASD: Autism Spectrum disorder, GDD: Global Developmental Delay |                 |            |

**NSW/ACT CP Register:** At the time of data extraction, a total of 2,880 individuals with CP were recorded on the NSW/ACT CP Register for birth years 1995–2012, of which 2,693 (94%) had a residential postcode available. Of those with a recorded postcode, there were 389 children up to 18 years residing in SWS (16.9%) with a confirmed diagnosis of CP and a total of 2,304 children in the rest of NSW (Table 2). The rates of CP were similar between SWS and NSW population (1.86 vs. 1.85 per 1,000). The cohort of children with CP in SWS had a higher proportion of children functioning within the Gross Motor Classification System (GMFCS) levels IV-V (31.1%) compared to those living in the rest of NSW (23.8%) (P = 0.002). A higher proportion of children with CP and intellectual impairment was reported in those residing within SWS (54.0%) compared to the rest of NSW (44.7%) (P < 0.001).

Table 2

Children with cerebral palsy (CP), types and co-morbidities, by South-Western Sydney residence versus New South Wales

|  | South Western Sydney<br>N (%) | Rest of NSW<br>N (%) | Total<br>N (%) | P-Value |
|--|-------------------------------|----------------------|----------------|---------|
| <b>Predominant motor type at age 5 years</b> |                               |                      |                | 0.088   |
| Spastic monoplegia/hemiplegia                |                               |                      |                |         |
| Spastic diplegia                             | 115 (29.6)                    | 775 (33.6)           | 890 (33.0)     |         |
| Spastic triplegia/quadruplegia               | 89 (22.9)                     | 487 (21.1)           | 576 (21.4)     |         |
| Ataxic                                       | 98 (25.2)                     | 462 (20.1)           | 560 (20.8)     |         |
| Dyskinetic                                   | 10 (2.6)                      | 102(4.4)             | 112 (4.2)      |         |
| Hypotonic                                    | 25 (6.4)                      | 171 (7.4)            | 196 (7.3)      |         |
| <b>Total</b>                                 | 17 (4.4)                      | 100 (4.3)            | 117 (4.3)      |         |
| Unknown                                      | <b>354</b>                    | <b>2097</b>          | <b>2451</b>    |         |
|  | 35 (9.0)                      | 207 (9.0)            | 242 (9.0)      |         |
| <b>GMFCS level at age 5 years</b>            |                               |                      |                | 0.002*  |
| Level I-III                                  | 241 (62.0)                    | 1590 69.0)           | 1831 (68.0)    |         |
| Level IV-V                                   | 121 (31.1)                    | 548 (23.8)           | 669 (24.8)     |         |
| <b>Total</b>                                 | <b>362</b>                    | <b>2138</b>          | <b>2500</b>    |         |
| Unknown                                      | 27 (6.9)                      | 166 (7.2)            | 193 (7.2)      |         |
| <b>Epilepsy</b>                              |                               |                      |                | 0.269   |
| Yes  | 112 (28.8)                    | 666 (28.9)           | 778 (28.9)     |         |
| No   | 180 (46.3)                    | 1235 (53.6)          | 1415 (52.5)    |         |
| <b>Total</b>                                 | <b>292</b>                    | <b>1901</b>          | <b>2193</b>    |         |
| Unknown                                      | 97 (24.9)                     | 403 (17.5)           | 500 (18.6)     |         |
| <b>Intellectual impairment</b>               |                               |                      |                | <0.001* |
| Yes  | 210 (54.0)                    | 1030 (44.7)          | 1240 (46.0)    |         |
| No   | 97 (24.9)                     | 880 (38.2)           | 977 (36.3)     |         |
| <b>Total</b>                                 | <b>307</b>                    | <b>1910</b>          | <b>2217</b>    |         |
| Unknown                                      | 82 (21.1)                     | 394 (17.1)           | 476 (17.7)     |         |
| <b>Vision impairment</b>                     |                               |                      |                | 0.208   |
| Yes  | 128 (32.9)                    | 739 (32.1)           | 867 (32.2)     |         |
| No   | 164 (42.2)                    | 1111 (48.2)          | 1275 (47.3)    |         |
| <b>Total</b>                                 | <b>292</b>                    | <b>1850</b>          | <b>2142</b>    |         |
| Unknown                                      | 97 (24.9)                     | 454 (19.7)           | 551 (20.5)     |         |
| <b>Hearing impairment</b>                    |                               |                      |                | 0.312   |
| Yes  | 53 (13.6)                     | 300 (13.0)           | 353 (13.1)     |         |
| No   | 234 (60.2)                    | 1564 (67.9)          | 1798(66.8)     |         |
| <b>Total</b>                                 | <b>287</b>                    | <b>1864</b>          | <b>2151</b>    |         |

|   |            |             |             |        |
|---|------------|-------------|-------------|--------|
| Unknown   | 102 (26.2) | 440 (19.1)  | 542 (20.1)  |        |
| <b>Speech impairment</b>  |            |             |             | 0.033* |
| Yes   | 221(56.8)  | 1303 (56.6) | 1524 (56.6) |        |
| No  | 85 (21.9)  | 669 (29.0)  | 754 (28.0)  |        |
| <b>Total</b>  | <b>306</b> | <b>1972</b> | <b>2278</b> |        |
| Unknown   | 83(21.3)   | 332 (14.4)  | 415 (15.4)  |        |
| <p>Note: Unknown proportion for each variable is calculated from the total, all other proportions and findings are from 'known' data. GMFCS, Gross Motor Function Classification System. The SWS population for children aged 5 -19 years is 209,151 and the NSW population for children aged 5-19 is 1,242,881 from HealthStats NSW <sup>28</sup></p> <p>*Significant, significance level set at p&lt;0.05</p> |            |             |             |        |

**SWISH:** Of the 14,546 newborns screened in 2018 in SWS, there were 32 cases of sensori-neural hearing loss (SHL) (prevalence: 2.2/1000), 17 cases of unilateral SHL (prevalence: 1.1/1000), and 15 cases of bilateral SHL (prevalence 1.1/1000).

**RIDBC:** Table 3 reports aggregated data on children by the severity of vision impairment (VI) for SWS and the rest of NSW. In SWS, 61% of children registered with RIDBC had severe VI or were blind compared to 39% of children in the rest of NSW who were registered with RIBDC (P < 0.003).

Table 3  
Children with visual impairment from RIDBC registry for 2018

| Visual Impairment  | SWS       | SWS (%)     | Rest of NSW | Rest of NSW (%) |
|--|-----------|-------------|-------------|-----------------|
| Mild VI  | 1         | 2.3%        | 50          | 22.4%           |
| Moderate VI  | 16        | 36.4%       | 85          | 38.1%           |
| Severe VI  | 10        | 22.7%       | 44          | 19.7%           |
| Blindness  | 17        | 38.6%       | 44          | 19.7%           |
| <b>Total</b>   | <b>44</b> | <b>100%</b> | <b>223</b>  | <b>100%</b>     |
| <b>Pearson's Chi-squared Test P-Value = 0.003</b>  |           |             |             |                 |
| <p>Note: RIDBC: Royal Institute for Deaf and blind Children. VI: Visual Impairment. SWS: South Western Sydney. NSW: New South Wales.</p> |           |             |             |                 |

**Department of Education data for children accessing support classes:** Table 4 reports on the number of students in support classes by disability type, as classified by the NSW Department of Education. There was a marked increase in children with ASD and moderate to severe Intellectual Disability accessing support classes in SWS compared to the rest of NSW. Of all students with special needs, there were 16.8% students with ASD in SWS and 8.5% in the rest of NSW. Similarly, 29.7% of students had moderate to severe intellectual disability in SWS and 24.4% in the rest of NSW. The percentage of students with Autism or Autism with moderate intellectual disability in SWS compared to the rest of NSW was 45.4%, with 27.4% of support classes for children in these categories located in SWS. Similarly, although 29.2% of students from NSW with moderate to severe intellectual disability lived in SWS, 17.3% of support classes for this category were in SWS.

Table 4  
Students with Disability in Support Classes (SWS versus NSW)

| Proportions of Students with Disability and Support Classes | Students Residing In |               |             | Support Classes Located in |             |             |
|---|----------------------|---------------|-------------|----------------------------|-------------|-------------|
|   | SWS                  | NSW           | RR          | SWS                        | NSW         | RR          |
| Autism Spectrum Disorder                                    | 741 (26%)            | 1581          | 3.26        | 61                         | 234         | 1.81        |
| Moderate Intellectual Disability and Autism                 | 240 (31%)            | 578           | 2.89        | 28                         | 91          | 2.14        |
| Moderate to Severe Intellectual Disability                  | 1320 (17%)           | 4514          | 2.03        | 55                         | 318         | 1.2         |
| Mild Intellectual Disability                                | 1046(18%)            | 3948          | 1.84        | 47                         | 268         | 1.22        |
| Physical Disability   | 15(6%)               | 121           | 0.86        | 1                          | 16          | 0.43        |
| Sensory Disability (Visual or Hearing Impairment)           | 104(14%)             | 179           | 4.04        | 3                          | 21          | 0.99        |
| Students in classes or Classes with Mixed Disability        | 469 (8%)             | 4856          | 0.67        | 39                         | 506         | 0.54        |
| <b>Total</b>  | <b>3935*</b>         | <b>15,777</b> | <b>1.56</b> | <b>234</b>                 | <b>1454</b> | <b>0.95</b> |

\*This total number does not include children supported in education system for emotional and behavioural disorders. Data only for ages 0–18 years. RR calculated using SWS Population NSW Health Stats. Percentage is students in support classes in SWS compared to NSW. The counts of Students and Classes are based on August 2018 School Term commencement.

**NDIS participants:** Table 5 enumerates the number of child participants (up to 18 years of age) receiving funding for accessing support and services for specific diagnosis for SWS compared to the rest of NSW. The cohort of participants from SWS formed about 15% of the NSW participants.

Table 5  
NDIS participants (0–18 years) for SWS vs. NSW up to quarter of July to September 2020

| Diagnostic classification       | NSW    | SWS  | Proportion (%) | Relative Risk |
|---------------------------------|--------|------|----------------|---------------|
| Autism Spectrum Disorder        | 32,736 | 5156 | 15.75          | 1.09          |
| Cerebral Palsy                  | 2228   | 314  | 14.1           | 0.97          |
| Developmental Delay /GDD        | 11854  | 1424 | 12.01          | 0.83          |
| Intellectual Disability         | 8699   | 1401 | 16.1           | 1.4           |
| Hearing Impairment              | 3031   | 495  | 16.3           | 1.13          |
| Visual Impairment               | 609    | 93   | 15.3           | 1.05          |
| GDD: Global Developmental Delay |        |      |                |               |

## Discussion

To the best of our knowledge, this is the most comprehensive and recent attempt to estimate the prevalence of various types of childhood neurodisabilities in a disadvantaged geographical region in Australia, using readily available data sources. Our analysis suggests that there is a greater proportion of children with disabilities in SWS compared to the rest of the state and that ASD is the most common neurodisability presenting to public developmental services. According to the most recent data on people with a disability from the ABS, the prevalence of any developmental disability in Australia increased from 6.9–7.42% between 2009 and 2015; but this did not specify the types of childhood disabling conditions.<sup>31</sup> We know child disability is common, but robust current estimates to inform planning and service provision are entirely lacking. Available data sources were incomplete and inadequate. Nevertheless, our analysis points to potential inequity in the access to disability support for children with neurodisability in SWS.

SWS as a region has been reported to have the highest number of communities in the lowest decile as per the Index of Relative Socio-economic Advantage and Disadvantage (IRSAD),<sup>32</sup> and the fifth most socially disadvantaged region in Australia.<sup>32</sup> The region also

has the highest refugee intake in the state of NSW, a high culturally and linguistically diverse population,<sup>33</sup> all of which may contribute to the current increased proportion of children with disability. In their systematic review of the association between disabling conditions in childhood and socio-economic disadvantage, Spencer et al (2015) concluded that there was a strong association in high income countries between childhood disability and social disadvantage, with risk estimates being highest for intellectual disability.<sup>13</sup> Australian data on childhood disability confirms this finding, with higher representation of children with severe disability among low-income households.<sup>32</sup> Similarly, analysis of disability data from the United Kingdom points to children with disability being more likely to live with low-income, deprivation, debt and poor housing.<sup>8</sup> On the other hand, while the majority of children with a disability live in low/middle income countries and despite socially and biologically plausible mechanisms underlying the association of low socio-economic status with childhood disability, empirical evidence from quantitative studies is inconsistent and contradictory.<sup>34</sup>

We focused on the best possible diagnostic specific data sources that enumerated children with disabilities in SWS and NSW. National levels data sets such as Australian Early Development Census (AEDC) or the ABS datasets are limited in exploring regional inequities in childhood disabilities as they enumerate proportions of children with disabilities at the state and national level.<sup>35 36</sup> These datasets can hide regional urban health and social inequalities.<sup>37</sup> We also focused specifically on neurodisability and conditions that were most relevant from the clinical and health service delivery perspectives: ASD, GDD, CP, Intellectual Disability, and sensory impairments including hearing and vision impairment. These diagnostic groups align with the intellectual and sensory/speech impairments from the 2015 Survey of Disability, Ageing and Carers (SDAC) conducted by Australian Bureau of Statistics,<sup>36 38</sup> and the five core development domains used by AEDC Census.<sup>35</sup>

While there is a range of developmental assessment services that exist for children in SWS region and NSW, including private paediatric and psychology clinics, the information from the CDAS database represented the caseload of children seen with a disability presenting to a public developmental diagnostic service. In SWS, approximately two-thirds of children in the developmental assessment services were diagnosed with ASD or ASD with GDD. This information correlates with the increasing prevalence of ASD globally, partly due to the changes in the diagnostic criteria for ASD in the 5th edition of the Diagnostic and Statistical Manual (DSM-V).<sup>10</sup> Other reasons hypothesised for the increase in ASD prevalence are a greater awareness of this condition, diagnosis at earlier ages, and the recognition that ASD is a life-long condition that requires ongoing support.<sup>39</sup> A survey of Australian paediatricians also report that they diagnose ASD in 39–56% of children in their first ambulatory consultation.<sup>40</sup> We cannot provide population estimates of ASD and GDD based on this data source, but it indicates the burden of neurodisability conditions requiring diagnostic assessment at a district level.

In the CDAS data, 60% of children were of a CALD background; these children had an increased risk of having global developmental delay. Previous qualitative research in Sydney has shown that children from CALD backgrounds with developmental problems miss out both on developmental surveillance and early intervention, highlighting the need for increased resource allocation for appropriate care and public awareness.<sup>41</sup> A similar analysis of a child development service in a defined geography in the United Kingdom, found that children from Pakistani cultural background showed a higher prevalence than other groups of severe disability and severe visual and hearing impairments.<sup>42</sup> Children of Aboriginal background represented 6% of children seen at CDAS, which is three times above the population of Aboriginal children in SWS.<sup>43</sup> While there is limited quantitative data on children with disability in Aboriginal populations, there is evidence from SWS that, even in the urban setting, Aboriginal children are at greater risk of developmental disability compared to non-Aboriginal children.<sup>44 45</sup> Given the postulated excess burden of childhood disability in Aboriginal populations, there is limited published literature or robust data in Australia on any conditions apart from hearing loss and learning disabilities consequent of otitis media.<sup>46</sup> Other public clinical services for vulnerable children and youth in SWS also document high levels of developmental disability, such as over 40% of the refugee clinic cohort,<sup>26</sup> and over a quarter of Aboriginal children in foster care.<sup>47</sup>

The prevalence of CP in SWS (1.86/1000) is similar to the rest of the NSW population. However, there was an increased severity of functional and intellectual impairment in the children with CP in SWS. Our findings concur with a recent Australian study describing an increased risk of non-ambulatory status, moderate-to-severe intellectual impairment and presence of severe comorbidities in individuals with CP born in low socioeconomic status neighbourhoods like SWS.<sup>48</sup> It is likely that there is under ascertainment even with this register, as there may be newly arriving children of migrant and refugee background who do not get a timely diagnosis of



cerebral palsy. Further research is needed to explore the factors influencing the increased likelihood of severe functional impairment in CP in such vulnerable populations, as well as mechanisms to enhance access to their essential health care needs.

Data from the RIDBC showed that in SWS there was increasing severity of visual impairment compared to NSW. RIDBC data has under ascertainment, as parents self-select to register their children on the RIDB registry. Newborn hearing screening on the other hand is almost complete and very accurately represents population prevalence. While we do not have contemporaneous data to compare with the rest of the state, the rate of neonatal SHL is similar in SWS to the global prevalence of this condition.<sup>49</sup>

Using Department of Education data for children with disabilities requiring supports, we found that the proportion of children with intellectual delay and ASD accessing supported education were significantly higher in SWS than the rest of NSW. We noted that SWS had disproportionately fewer classes for physical disability and sensory impairments than the rest of NSW. This is despite higher burden of functional impairments for children with CP and visual impairment in SWS, indicating potential inequity in the level of specialist educational supports provided in this region.

Data from NDIS indicates that there is a slight increase in proportion of children accessing disability supports for intellectual disability, but all other conditions were on par with SWS population. This suggests that significant numbers of children with neurodisability in SWS are not accessing NDIS. A linked dataset between a state-wide register and NDIS participants is needed to accurately ascertain this and we, therefore, argue for a state-wide disability register that links with NDIS datasets as well as with the National Disability Data Asset.<sup>50</sup>

## Limitations Of The Study

We did not make any comparison from the national data sets of childhood disability in Australia, as the aim of the study was to focus on a specific region of the largest state in Australia, with a high proportion of multicultural populations. We acknowledge that all our data sources are incomplete and inadequate, particularly from the Department of Education, as only children in support classes in public schools are counted, whereas children in private or independent schools or mainstream classes with additional supports are not included in the available data sources. There are several other sources of information that we did not have access to, including the unregulated private child developmental diagnostic assessment services and other private allied clinical services.

## Conclusion

From the best available sources of data, we have determined that there is a significant proportion of children with disability in SWS, with evidence of increasing proportion towards the more severe ends of the disability spectrum. ASD is the most common diagnostic category presenting to our developmental diagnostic services. The socio-demographic profile of SWS, including the large refugee population, low health literacy in certain migrant groups and poverty, likely contribute to the picture of childhood disability in this region. Despite the greater needs indicated, access to disability and special education support in SWS appear to be inadequate. The quality of data overall is sub-optimal, however, we have attempted to make sense of the best available public data sources. Without adequate real-time information on the prevalence of childhood disability in Australia, appropriate planning for support and intervention delivered at scale is hindered. We therefore strongly advocate for a comprehensive Statewide or national register to enable surveillance and resource allocation for effective management of childhood disability. A register will allow for the early detection of trends, enable targeted health service planning and facilitate evidence-informed advocacy for our most vulnerable populations.

## Abbreviations

ACT- Australian Capital Territory

AEDC- Australian Early Development Census

ASD- Autism Spectrum Disorder

CALD- Culturally and Linguistically Diverse

CDAS- Child Development Assessment Service

CP- Cerebral Palsy

GDD- Global Developmental Delay

IRSAD- Index of Relative Socio-economic Advantage and Disadvantage

NSW- New South Wales

RIDBC- The Royal Institute of Deaf and Blind Children (RIDBC)

SDAC- ABS Survey of Disability, Ageing and Carers

SWISH-State-wide Infant Screening-Hearing

SWS – South Western Sydney

## Declarations

**Ethics approval and consent to participate** – Ethics approval was obtained through the SWS Local Health District Human Research Ethics Committee. Additional ethical approval was granted for the use of the NSW/ACT CP Register data by the Cerebral Palsy Alliance Human Research Ethics Committee.

**Consent for publication** - All authors have consented for publication. No individual patient data is presented, therefore, consent was not required from participants

**Availability of data and materials** - All data is available at reasonable request from corresponding author

**Competing Interest** - None

**Funding** - None

**Authors Contribution** - PG & MD collected and analysed data, KO provided data analysis of CP data, BJ provided statistical oversight, SV contributed to data analysis of CDAS data, GG provided data analysis of Visual impairment data, SR conceived the project and provided project lead. All authors contributed to paper writing and intellectual content.

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