Learning from Where's Wally? Measuring a 'missing population' of families caring for children with disability.

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1. Introduction

The popular illustrated children's books 'Where's Wally?' present a puzzle of finding a single character within a busy scene populated by many hundreds of other characters. Researchers interested in missing populations face similar challenges. They have to identify and accurately measure small groups of critical interest while filtering out the 'noise' created by the background population. There may be 'red herrings' in the way of that goal. In the books, Wally wears a distinctive costume of a red and white striped shirt and hat. The inclusion of red and white coloured objects or similar shaped people in different colours served to increase the complexity of the task for readers. Missing populations may be similarly camouflaged. Research into missing populations needs to sort data carefully using parameters which are most likely to identify members of the sub-group, before undertaking appropriate analysis. Results need to be confirmed using other data sources, like using the checklist found at the end of every 'Where's Wally?' story.

This paper investigates families caring for a child or young person aged 0 to 19 years with disability in Australia. This group makes up an estimated 1.65% of the Australian population as shown in Table 1. The economic and social costs associated with unmet disability need make this group a key target of core social policies, such as disability support, education, health and social welfare. Yet, this group is under-represented in the data commonly used to inform the development of social policy. The hard-to-reach nature of this population has also inhibited other demographic research, both within Australia and internationally. The paper discusses challenges experienced in identifying this missing population and construction of appropriate analytical models, while also considering the learning process, benefits and limitations of approaches undertaken.

Table 1: Persons in Australia in 2009 by Age Group and Disability Status

	Disability Status				Total	
Age Group	Has a disability	%	No disability	%		%
0-19 years	356,001	1.71	4,957,981	23.81	5,313,982	25.52
20-39 years	541,203	2.60	5,552,800	26.67	6,094,003	29.27
40-59 years	1,057,382	5.08	4,600,924	22.10	5,658,307	27.18
60-79 years	1,305,436	6.27	1,826,134	8.77	3,131,5696	15.04
80+ years	425,159	2.04	198,350	0.95	623,509	3.00
Total	3,685,181	17.70	17,136,189	82.20	20,821,370	100.00

Data source: Australian Bureau of Statistics Survey of Disability, Ageing and Carers 2009 CURF

Substantial research on socio-demographic factors of families with a child with disability is available from the United States of America, due to the existence of large sub-groups in national data. Studies indicate children with disability are significantly more likely than children without disability to experience parental divorce, to be living in a sole parent household or to be living with their mother only (Corman and Kaestner 1992; Mauldon 1992; Joesch and Smith 1997; Reichman, Corman et al. 2004; Cohen and Petrescu-Prahova 2006). This research notes living in a sole parent family places children at increased risk of economic hardship.

Research in Australia into carers of people of all ages with disability indicates that negative impacts include reduced access to economic resources (Edwards, Higgins et al. 2008). However, these findings are based analysis of the entire Survey of Disability, Ageing and Carers, where an estimated 47% of persons with disability are aged 60 or over. Children and young people aged 0 to 19 years comprise less than 10% of all persons with disability. Childhood disability is either congenital (present at birth) or acquired through illness, accident or toxin exposure. The impact of disability reaches beyond the individual, as ongoing care and support is usually provided by the child's family. De Vaus finds 70% of carers of a child with a disability report impacts on their financial status (De Vaus 2004).

Research into children and young people offers the opportunity to develop policy responses appropriate to developmental stages. The care situation of a 9 year old with disability may be substantially different to that of a 29 year old or an 89 year old. Parents caring for children with disability in Australia attribute higher risks of separation or divorce to the emotional stress and financial costs of caring for a child with disability (National People with Disabilities and Carer Council 2009; Parliament of Australia House of Representatives Standing Committee on Family 2009). Identification of families at increased risk of economic hardship informs the development of

appropriate social policy responses. The issue of missing populations means that adequate evidence of the potential economic vulnerability of families with a child with disability remains substantially unaddressed.

Kennedy and Perz identify three key issues for data relating to missing populations: conceptualization, coverage and reporting (Kennedy and Perz 2000). Self-identification or conceptualization of disability is an issue. Families may not identify their personal situation with terms such as 'carer', 'disability' or 'chronic health condition'. Even if identified and contacted, coverage is hard to achieve as refusal rates for families in vulnerable circumstances is often high. Non-representative sampling leads to potential bias issues and findings, while transferable, cannot be generalised to the population. These factors limit many researchers to secondary analysis of national data collected by national statistics agencies (such as the Australian Bureau of Statistics). Problems of conceptualization, coverage and reporting also arise in population data. Under-reporting of disability occurs from issues with self-identification and question structure (Australian Bureau of Statistics 2006). Sub-sample sizes in national population data are also usually small which limits options for analysis. Reporting is also an issue. Sub-sample data is often randomly adjusted by the Australian Bureau of Statistics to protect recipient confidentiality. Data may be restricted to aggregated tables. These issues present considerable challenges which must be overcome to locate the story of the sub-sample within a crowded population picture.

Table 2: Research Hypotheses

Hypothesis 1	Children with disability are more likely to live in areas of relative economic disadvantage than children with no disability.
Hypothesis 2	Older children with disability are more likely to live in areas of relative economic disadvantage than younger children with disability.
Hypothesis 3	Children with disability are more likely than children with no disability to live in families with lower income.
Hypothesis 4:	Children with disability are more likely to live in larger families than children with no disability.
Hypothesis 5	Children with disability are more likely to have moved house than children with no disability.

2. Data and method

Two data sources were selected. The Australian Census of Population and Housing 2006 has a broad but shallow measure of disability using need for core activity assistance. This is a conservative measure which identifies persons with severe or profound levels of disability. The Australian Survey of Disability, Ageing and Carers (SDAC) is a periodic household survey using stratified random sampling. Measures of disability are comprehensive and dense levels of data are collected.

Census 2006: An aggregated table of age by need for core activity assistance for persons aged 0 to 19 years in 2006 was obtained using data from the Census. This table was divided into geographical locations according to statistical sub-district boundaries (SSD) defined by the Australian Bureau of Statistics. Data on children and young people for each SSD was matched to SSD area data obtained from the Index of Economic Resources (IER). The IER is also based on the 2006 Census and provides an indication of an area's lower or greater relative access to economic resources.

The IER is recommended for assessing "access to economic resources and the associated ability to participate in society" (Australian Bureau of Statistics 2006). The independent variable of 'area category' was constructed by transforming the SSD index scores into an ordinal scale from 1 to 4. Allocation of the area category was decided by the largest proportion of population usually resident within each area category sub-grouping within each SSD.

Table 3: Area Categories

Category	*Highest percentage of the SSD's population*
1	Deciles 1 (the area of lowest disadvantage)
2	Deciles 2-5 (below the IER mean)
3	Deciles 6-9 (above the IER mean)
4	Deciles 10 (the area of highest advantage)

Area category scores were then allocated to each SSD in the aggregated table of age by need for core activity assistance for analysis.

SDAC 2009: Data was merged at household, income unit, family and person levels. A core group of persons with all levels of disability aged 0 to 19 years was identified by setting a series of parameters based on key characteristics. Family income deciles data was combined into 3 groups: low (deciles 1 to 3, middle (deciles 4 to 7) and high income (deciles 8 to 10) for statistical analysis.

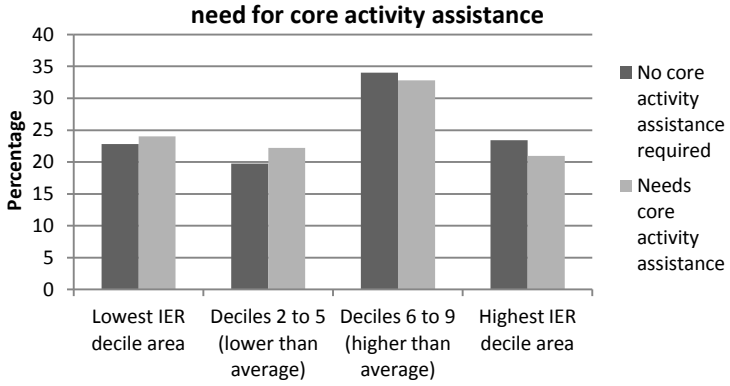
3. Results

Census 2006: Children and young people aged 0 to 19 requiring core needs activity assistance were significantly more likely than other children and young people to live in areas of relative economic disadvantage and significantly less likely to live in areas of relative economic advantage.

Comparison of different age groups of children with need for core activity assistance is also significant with small effect size. Children aged 0 to 9 were 1.02 times more likely than the group aged 10 to 19 to live in areas scoring in the lowest deciles of the IER. Younger children with need for core activity support were also significantly more likely than older children to live in areas of relative economic advantage, but less likely to live in areas of with lower than average access to economic resources.

SDAC 2009: Children aged 0 to 19 years with disability were significantly more likely to live in a family with a low or middle income and less likely to live in a family with high income than children the same age with no disability. Children with disability are 1.7 times more likely to live in a family with 3 or more children aged less than 15 than a child with no disability. While a majority of Australian families did not move house in 1991 to 2009, families with a child or young person with disability were 5 times more likely to have moved than families with no child disability.

Figure 1: Place of usual residence for children and young people in Australia aged 0 to 19 years by need for core activity assistance

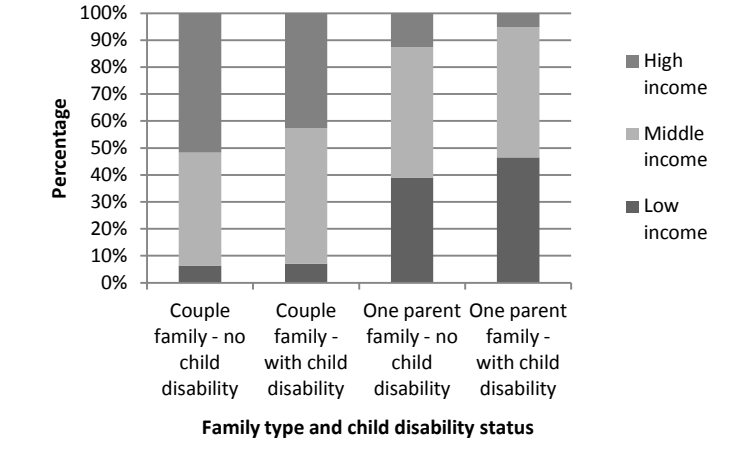


4. Discussion

Comparison of results obtained from the Census of Population and Housing 2006 and the Survey of Disability, Ageing and Carers 2009 confirms that a number of relationships exist between child disability status and economic resources. Families with a child with disability in Australia are more likely to live in families with low or middle income levels and less likely to live in families with high income levels, when compared to families with a child with no disability. They are also more likely to live in areas of relative economic disadvantage and less likely to live in areas of relative economic advantage.

Differences between older and younger cohorts of children with need for core activity support were mixed. Evidence suggests a cumulative process of economic disadvantage may occur, as negative impacts may take several years to diminish accumulated resources, but cohort effects are an artefact of cross-sectional data. For example, younger children may have benefitted from infant health programs leading to earlier diagnosis. Diminished resources may necessitate a move to cheaper housing options found in areas of relative economic disadvantage. This creates a compelling case for future investigation of temporal issues using longitudinal data.

Figure 2: Income group by family type and child disability status in Australia in 2009



Families with a child with disability are 1.7 times more likely to have 3 or more children aged less than 15 years. Families with more children are at higher risk of economic disadvantage due to increased costs and reductions in capacity for parental workforce participation. Further research could investigate the timing of births in families with a child with disability and elicit information on fertility choices.

Families with a child with disability are also 5 times more likely to have moved house than families with a child with no disability. Moving house may be a reflection of changed economic circumstances or a response to other issues such as increased need for space. However, it can also be a reflection of the reduced security of tenure associated with renting a house. Families with lower incomes are more likely to be restricted to rental accommodation. House moves are an issue of concern as repeated moves may diminish family economic resources, create dislocation from social supports and interrupt schooling. Again, this would be a valuable area for future research.

Triangulation of analysis from two datasets adds strength to the overall findings. Children with disability are a very small group within each dataset. Parameters have to be set to enable accurate identification, especially when structures used for reporting the dataset do not match the target group. While effect sizes were often small, statistical significance was achieved for all analysis and in each of the datasets.

Correlation does not imply causality. Having a child with disability may have a negative impact on family income. Alternatively, people on low incomes may be more likely to have a child to have a child with disability. There may be a combination of these factors involved or there may be other factors which are contributing to the relationship between child disability status and economic disadvantage. Parental workforce participation and family type (couple or one parent) are key issues which contribute to economic resources in families. While beyond the scope of this paper, they are an essential area for future research.

The biggest challenges faced in this research came from the constraints associated with missing populations. Conceptualization problems occur from self-identification barriers. Issues of concern to marginal groups are rarely a matter of national priority. Coverage is also an issue. Small numbers of cases make these populations hard to find in national data and low participation rates typical of marginal groups restrict data availability from other surveys. Researchers need to be creative in their strategies to uncover the parameters of their population, while also avoiding the 'red herrings' of data which may be a similar colour or shape as your missing population. When data is found, inflexibility in reporting often prohibits the use of many statistical tests. This is especially an issue when working with small sub-samples as measures to protect confidentiality, such as aggregated tables and random adjustment, can render the data unusable. Constant tension is created by the need to consolidate categories to have sufficient sample sizes to attain statistical significance, and the associated sacrifice of loss of detail. While small effect sizes are offset by the triangulation of data, the challenge of building robust regression models with small sub-samples is substantial.

The findings on children with disability outlined in this paper are consistent with the literature and have compelling implications for social policy development. It is evident that many children with disability face multiple disadvantages at economic and social levels on top of the disadvantage already created by their disability. Services for children with disabilities need to be targeted in areas of relative economic disadvantage. Supports for families need to identify and address economic hardship issues, enable security of housing tenure, and address the issue of complex or multiple disadvantages.

Table 4: Results for Research Hypotheses

Hypothesis 1	Children with disability are more likely to live in areas of relative economic disadvantage than children with no disability.	Supported
Hypothesis 2	Older children with disability are more likely to live in areas of relative economic disadvantage than younger children with disability.	Partially supported
Hypothesis 3	Children with disability are more likely than children with no disability to live in families with lower income.	Supported
Hypothesis 4:	Children with disability are more likely to live in larger families than children with no disability.	Supported
Hypothesis 5	Children with disability are more likely to have moved house than children with no disability.	Supported

5. References

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