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Australian children with disabilities' unmet support needs

**Evidence from the Better Support for Kids
with Disabilities survey**

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Research Summary

Why was the research done?

The National Disability Insurance Scheme (NDIS) represents a milestone in Australian social policy. But despite the importance of the NDIS for Australians with disabilities, there are ongoing concerns regarding equitable access to support that risk undermining the effective operation of the scheme. Previous evidence on this topic has been largely qualitative, with no existing quantitative evidence of equitable access to support for children with disabilities. Consequently, we collected a new survey (the Better Support for Kids with Disabilities survey) of parents or carers of children with disabilities (aged 2-17), focussing on use of services, experiences of disability support, and unmet needs for support.

What were the key findings?

The current article analyses unmet needs for support among Australian children with disabilities using data from the Better Support for Kids with Disabilities survey. Our findings show that most children with disabilities (83%) have unmet needs for support, with a sample average of 2.3 different unmet needs. The most common unmet needs were for therapy, school-based support, and support workers. The most common reasons for unmet needs were exclusion of the support from the child's NDIS plan, provider availability, and cost. Unmet needs were inequitably distributed: after accounting for differences in the child's functional difficulties and disability types, higher number of unmet needs was associated with lower family income, the presence of adults with disabilities, single parent families, and residence in regional or remote areas.

What does this mean for policy and practice?

Our findings indicate that there are substantial unmet needs for support among Australian children with disabilities and that these unmet needs are inequitably distributed. As state and federal governments embark on the ambitious program of reforms proposed by the recent NDIS review, there is a pressing need for monitoring to track patterns and changes in equitable access to support. Existing data is insufficient for this task due to the absence of dedicated surveys of families of children with disabilities and the lack of measures of functional limitations.

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We acknowledge the Traditional Custodians of the lands on which we work and live across Australia.
We pay our respects to Elders past and present and recognise their continued connections
to land, sea and community.

Introduction

Disability support systems in Australia have undergone major change over the past decade, with the new National Disability Insurance Scheme (NDIS) commencing from 2013 and full implementation in 2020 (NDIS, n.d.). Its introduction promised a transformational shift from the long-standing, fragmented state-based system to a Federally governed system to support Australians with disability from birth to 65 years of age (Devine et al., 2021; Gavidia-Payne, 2020). Specifically, the NDIS was designed to provide choice and control to the participants, claiming to place the individual with disability at the centre of decision-making regarding the supports they require (Devine et al., 2021; Gavidia-Payne, 2020). Under this insurance model, participants are directly provided with the funding to access the supports of their choosing, rather than needing to rely only on available government funded and not-for-profit services (Gavidia-Payne, 2020).

Current data show that as of 2024, 661,267 Australians were registered with the NDIS, with 343,092 – or 52% being under the age of 18 (NDIS, 2024). Ensuring that young people with disabilities are provided with the supports they need is crucial due to the known benefits of early childhood intervention such as improved skill development, independence and functioning, and reduced reliance on formal and informal supports long-term (Pye et al., 2024; Ranashinghe et al., 2017). Further, as parents and caregivers of children with disability remain the primary source of support throughout the individual's life a plethora of literature (e.g., Chen et al., 2023; Hoyle et al., 2021) has highlighted the health and wellbeing challenges these families experience further emphasising the need for appropriate supports.

Although designed to allow parents and caregivers of children with disability the 'choice and control' of how their child accesses the necessary supports, the closing of many governments funded community services this has resulted many parents feeling alone and overwhelmed as they attempt to navigate an increasingly complex system (Moore, et al.,

2019). To better understand the experience of these families accessing supports for their children through the NDIS several qualitative studies have been conducted (e.g., Gavidia-Payne, 2020; Ranasinghe et al., 2017; Tracey et al., 2018). These studies have consistently highlighted several challenges families experience accessing supports for their child resulting in added, unnecessary stress. For example, within a 2020 study conducted by Gavidia-Payne, specific challenges identified by parents included: difficulty navigating the many administrative tasks required by the National Disability Insurance Agency (NDIA); the wait time between initiating contact with the NDIA, gaining funding, and then accessing the required services; lack of apparent disability specific knowledge of the NDIA staff; lack of transparency behind decisions made; and lack of consideration for the knowledge expertise held by the families in relation to their children. Participants within this study also noted several inequities families experienced accessing the NDIS such as having a parent with a disability, living in a low-socioeconomic household, and living in rural and remote regions. Parents also noted that the amount of funding their child received appeared to be dependent on the parents' ability to advocate for their child's needs (Gavidia-Payne, 2020).

Within their systematic literature review of studies exploring the experience of parents of children with disability accessing supports through the NDIS, Russo and colleagues (2021), noted similar challenges. Amongst the eight articles identified within their review barriers discussed by the families included: feeling overwhelmed and overloaded by the information provided by the NDIA making it difficult for them to make informed choices; as well as the challenges experienced navigating the complex processes when attempting to engage with the NDIA, and locate appropriate service providers (Russo et al., 2021). Authors highlighted the same inequities experienced by many families as identified by Gavidia-Payne (2020), emphasising the impact that these inequities had on families receiving the necessary supports for their child. Further, parents and caregivers discussed the mental and emotional

fatigue they experienced needing to play a constant advocate role for their child to when working with the NDIA (Russo et al., 2021).

Parents and caregivers of children with disability face unique stressors impacting both their health and wellbeing (Chen et al., 2023; Hoyle et al., 2021). As such it is crucial that these families are provided with the supports that they need to not only facilitate their child's development, but to enhance the wellbeing of the whole family. Although providing valuable insights into the experience of families accessing supports for their child through the NDIS, inherent to qualitative studies current available research has relied on small sample sizes, with few large-scale quantitative studies currently available. As such, to further understand the challenges families experience accessing supports for their children through the NDIS, the current study addressed three primary research questions. First, what are the unmet needs for support of children with disabilities, and why do families believe these needs remain unmet? Second, how do unmet support needs differ by child characteristics, including functional difficulties, disability type, and age? Third, accounting for differences in children's functional difficulties and disability type, how are unmet support needs related to environmental factors including family- and area-level equity considerations including socio-economic status, single-parent families, cultural background, adult disability, and remoteness?

Methods

Data for analysis were drawn from the 'Better Support for Kids with Disabilities' (BSKD) survey. Ethics approval for the BSKD survey was granted by the University of Queensland Human Research Ethics Committee (Approval number 2024/HE001286). Participants provided implied consent to participate within this project through the completion of the survey.

Participant recruitment

Participants were recruited through Facebook advertising between July and October 2024. Individuals were able to complete the survey if they were a parent or primary caregiver of a child, or multiple children with disability between the ages of 2-17 years and resided in Australia. Parents and caregivers with more than one child with disability were asked to answer with respect to their oldest (within the 2-17 age range) child with a disability.

Measures

Unmet need: Unmet support needs were measured by asking ‘In the last 12 months, have there been any of the services or supports listed that your child has needed but could not get?’, with multiple choice options including ‘Therapy’, ‘Medical care’, ‘Aids, equipment, or assistive technology’, ‘School-based support for learning’, ‘Modifications to home environment’, ‘Support workers’, ‘Access to community activities’, ‘Transport’, ‘Other’ or ‘No unmet need’. Respondents were instructed to select all applicable categories. To assess the overall level of unmet need, a count of the number of types of unmet need, ranging from zero to nine was presented to participants.

Parents who indicated at least one unmet need were then asked ‘What were the main reasons why your child could not get the needed services or support?’ with choices including ‘Too expensive’, ‘No suitable provider in my area’, ‘Services not culturally appropriate’, ‘Services not inclusive’, ‘Services did not understand my child’s needs’, ‘Services too far away’, ‘Providers did not have availability’, ‘Services not included in my child’s NDIS plan’, ‘My child was too unwell to access services’, and ‘Other’.

Child functional difficulties and diagnoses: Child functional difficulties were assessed using the Washington Group/UNICEF Module on Child Functioning (Cappa et al. 2018; Loeb et al. 2018). Questions were differentiated by age (2-4 vs 5-17) and assessed a range of functional difficulties. Seeing, hearing, walking, communication, learning, and behaviour

difficulties were assessed for both age bands. Fine motor and play domains were assessed only for children aged 2-4, while self-care, remembering, concentrating, accepting change, making friends, anxiety, and depression were assessed only for those aged 5-17. Each type of difficulty was recoded into 'no functional difficulty' or 'moderate functional difficulty' or 'severe functional difficulty'. 'Moderate difficulty' was based on recommended cut-points for disability (Cappa et al. 2018), corresponding in most instances to a child who is reported to experience 'a lot of difficulty' with a given activity. 'Severe' difficulty corresponds to 'cannot do at all' for most domains, but is not ascertained for behaviour (2-4), anxiety (5-17), or depression (5-17) because for these domains the highest response category is already the recommended threshold (Cappa et al. 2018) for disability, meaning that the instrument does not permit further disaggregation into levels of difficulty. Given sample size constraints, we further grouped difficulties into seven domains: sensory (seeing, hearing), physical (age 2-4: walking, fine motor; age 5-17: walking), communication, cognitive (age 2-4: learning; age 5-17: learning, remembering, concentrating), social/behavioural (age 2-4: playing, behaviour; age 5-17: accepting change, making friends, behaviour), mental health (age 5-15 only: anxiety, depression), and self-care (age 5-17 only). Summary measures including highest level of difficulty across all domains (none, moderate, severe) and the number of domains with at least 'moderate' difficulty were calculated based on these groups.

Parents were also asked to report if a doctor had ever diagnosed their child with an ongoing disability. Due to sample size considerations, less common diagnoses were collapsed into the following groupings: autism, attention deficit hyperactivity disorder (ADHD), intellectual disability, other developmental disability, specific learning disabilities, and other disability or long-term health conditions.

Family background: A range of child, parent, family, and area characteristics were also collected. For the child, age was grouped as 2-4, 5-8, 9-12, and 13-17, reflecting distinct

stages of development and the upper limit (age 8) of NDIS access through the ECEI pathway. For parents, we recorded highest level of education (dichotomised to ‘degree’ or ‘no degree’), partnership status, Indigenous status, whether they speak a language other than English at home, age, and sex. At the family level, equivalised (using the ‘modified OECD’ scale) annual pre-tax income from all household members was also captured and log-transformed for analysis. Adult disability was captured using a binary yes/no item indicating whether any adult member of the household had a disability or long-term health condition that restricted everyday activity. Area level characteristics including the Australian Bureau of Statistics’ (ABS) Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) and remoteness (coded to ‘Major cities’, ‘Inner regional’, and ‘Outer regional/remote’) were linked at the postcode level.

Analysis

Descriptive analysis was used to summarise the prevalence and number of distinct unmet support needs and the reported reasons for unmet needs. To address the relationships of child and family characteristics with unmet support needs, Poisson regression was used to model the count of the number of unmet needs (ranging from zero to nine). Robust standard errors were employed to account for potential distributional violations. Missing data on covariates was dealt with using multiple imputation by chained estimation (MICE) with $m = 20$ imputed datasets.

Results

A total of 688 parents or primary caregivers completed the survey with 644 participants completing all questions relating to unmet needs for support. This resulted in a total sample size of 644 participants. Sample summary statistics are presented in table 1. Most children were school age and slightly less than two thirds were male. On average, children had 2.3 different functional difficulties, with social/behavioural (78.9%), cognitive (53%), and mental

health (47.8%) difficulties most common. Most children experienced ‘moderate’ functional difficulty, with relatively small proportions of ‘no difficulty’ (11.3%) or ‘severe difficulty’ (10.4%). Autism (72.7%), followed by ADHD (60.6%), mental health conditions (41.6%) and other disability/health condition (31.4%) were the most prevalent diagnoses reported.

Regarding parent and family characteristics, the sample appeared to overrepresent those with higher levels of education (69.2% with university degrees). Most respondents were female (95%), partnered (78.4%), non-Indigenous (97.4%), and did not speak another language at home (88.8%). Slightly less than half (43.9%) of households included an adult member with a disability and three quarters were in major cities (75.1%).

Insert Table 1 approximately here

Research question 1: What are the unmet needs for support of children with disabilities, and why do families believe these needs remain unmet?

Figures 1 and 2 show, respectively, the sample prevalence and number of different unmet support needs. Notably, most children in the sample – five out of every six – were reported to have at least one unmet need for support. On average, 2.3 unmet support needs were reported, with approximately one quarter of the sample reporting four or more different unmet support needs. The most common unmet need was for therapy, reported for just over half of the sample (50.6%). Other commonly reported unmet needs included school-based supports (43.9%), support workers (36%), access to community activities (29.4%), and aids or assistive technology (20.2%). Perhaps reflecting the primarily psychosocial disabilities included in the sample, relatively small proportions indicated unmet needs for transport (9.3%) or modifications to the home environment (7.8%). About one sixth (17.1%) of the sample reported ‘other’ unmet needs for support.

Insert Figures 1 and 2 approximately here

Reasons reported for unmet needs are shown in Figure 3. Exclusion from the child's NDIS plan (45.3%) was the leading reason for unmet needs. Separate analysis (not shown) indicated that this rises to 61% for children with a current NDIS plan. Provider availability (44.8%) and the absence of suitable providers in the area (30.2%) were also frequently reported. A combined 56% indicated either availability or the lack of suitable local providers. Cost (39.2%) was also a common barrier. The reported importance of cost varied strongly depending on whether the child had a NDIS plan, affecting only 28.5% of those with a plan in comparison to 69.8% of those without a plan (analysis not shown). Service level barriers, including services not understanding the child's needs (26.3%) or services not being inclusive (17.5%) also affected a substantial number of children – in combination, approximately one third. A small proportion of unmet need was attributed to the child being too unwell (6.3%) and 'other' (18.3%) reasons.

Research question 2: How do unmet support needs differ by child characteristics, including functional difficulties, disability type, and age?

Modelling results pertaining to the relationship between unmet need and children's age, functional difficulties, and disability type – is presented in Table 2. Because there was strong overlap between functional difficulties and disability type, these were analysed separately. Similarly, type of functional difficulty and summary measures (highest level, number) of functional difficulty are constructed from the same survey questions and are therefore effectively colinear. To ease interpretation, estimates are presented as incidence rate ratios (IRR), meaning that a parameter value of 1 is equivalent to no association. Model 1 shows estimates including only child age, with findings indicating higher levels of unmet support need among older children. Specifically, compared to pre-school aged children, those aged 9-12 experience approximately 40% more unmet support needs and those aged 13-17 approximately 50% more. This appeared to reflect the presence of greater needs among older

children, as age-related differences in unmet need largely disappeared after adjustment for functional difficulties or disability type (models 2-4).

Insert Table 2 approximately here

Model 2 incorporates type of functional difficulty. Estimates showed higher levels of unmet need (in the order of 26-40%) for children with cognitive, social/behavioural, mental health, or self-care difficulties. The presence of sensory, physical, or communication difficulties was not significantly associated with levels of unmet need, with incidence rate ratios close to 1. Switching to summary measures of functional difficulty (model 3), we found strong evidence of higher unmet support needs among children with a greater number of different functional difficulties – approximately a 22% increase in unmet need for each functional difficulty. Highest level of difficulty was associated with higher unmet need, although differences were not statistically significant. Notably, this does not reflect the lack of an association, but rather strong collinearity between highest level of difficulty and number of difficulties. Separate analysis (not shown) including only child age and highest level of difficulty indicated levels of unmet need roughly twice as high for children with ‘moderate’ difficulties and nearly three times higher for children with ‘severe’ difficulties in comparison to those with no functional difficulties.

Finally, model 4 replaces functional difficulties with disability (diagnosis) type. Autism (IRR = 1.52), intellectual disability (IRR = 1.41), and specific learning disabilities (IRR = 1.28) were associated with higher unmet support needs. Conversely, ADHD, mental health conditions, and other developmental disorders were not linked to higher support needs, although it is important to note that there is a high degree of co-occurrence. ‘Other disabilities and health conditions’ were also linked to higher unmet support needs (IRR = 1.30).

Research question 3: Accounting for differences in children’s functional difficulties and disability type, how are unmet support needs related to environmental factors including

family- and area-level equity considerations including socio-economic status, single-parent families, cultural background, adult disability, and remoteness?

Results for the relationship of unmet needs to equity considerations are presented in Table 3. With the aim of accounting as thoroughly as possible for any differences in children's need for support, all models adjust for child age, functional difficulties, and disability type. We first fitted four models to investigate different equity concerns separately including socio-economic status (parent education, household income), cultural background (indigeneity, language spoken at home), adult disability, partnership status, and area (remoteness, neighbourhood advantage). A sixth combined model includes all equity factors. The first model, for socio-economic status, shows a very strong inverse relationship between household income and unmet needs for support (IRR = 0.77). For parent education, however, the estimated IRR was close to 1 and not statistically significant. Model 2 addressed cultural background, with no association between either indigenous status or language spoken at home and child unmet support needs. The presence of an adult with a disability (model 3) was linked to approximately forty percent (IRR = 1.41) higher unmet child support needs, while children of partnered parents experienced lower unmet needs (model 4, IRR = 0.74). Regarding area differences (model 5), there was no association with neighbourhood advantage/disadvantage. Children living in inner regional (IRR = 1.25) or outer regional/remote (IRR = 1.38) areas, however, experienced higher levels of unmet need in comparison to those living in major cities. The combined model, with mutual adjustment for all equity factors, showed essentially identical conclusions albeit with minor attenuation towards the null. This suggests that different social determinants of equity largely affect unmet need independently.

Insert Table 3 approximately here

Discussion

The present study aimed to expand on current literature to understand the challenges parents and caregivers within Australia experience accessing supports for their child with disability. When addressing research question one in relation to the unmet support needs as perceived by the parents and caregivers of children with disability, overwhelmingly families believed that their children had support needs that remained unmet. Like previous studies exploring supports received by children with disability under the NDIS (Gavidia-Payne, 2020; Rangasinghe et al., 2017; Russo et al., 2021; Smethurst et al., 2020) reduced access to therapy services, support workers, community activities and aides and equipment were identified by participants, with availability and access to funds and service providers cited as the most common barrier. Children with disability are often supported by several therapeutic services such as occupational therapy, speech therapy and psychology (Pye et al., 2024). With the introduction of the NDIS, these services are most often provided in the community under a fee-for-service model, rather than government funded programs. This means that families rely on the funds be approved by NDIA to access these services. Within past studies (Gavidia-Payne, 2020; Russo et al., 2021), parents have explained that to receive the funds needed to support these different therapies parents required the knowledge of available services, as well as the skills to advocate for why these services would benefit their child. This has been suggested to result in many families not receiving the funds required to access the therapy services at the frequency and/or duration that would be beneficial for their child (Gavidia-Payne, 2020).

When able to advocate for their children, parents have described that they are often required to ‘fight’ for the supports and services their child requires such as aides and equipment, as well as access to community activities (Gavidia-Payne, 2020; Smethurst et al., 2020). Parents have cited the lack of knowledge of the NDIA staff in relation to the needs of

children and families with disability resulting in many family's requests deemed as not reasonable or necessary, or the responsibility of the parents (Gavidia-Payne, 2020; Smethurst et al., 2020). Within these studies parents have noted that if families do not have the knowledge, skill and emotional energy to continue to advocate for their child, then this would result in several of their child's needs going unmet. Further, for those children who do receive the funds requested to access supports, many parents report difficulties locating appropriate providers and are often met with long wait lists resulting in a further challenge to these families (Gavidia-Payne, 2020; Rangasinghe et al., 2017; Russo et al., 2021; Smethurst et al., 2020). The additional stressors of caring for a child with disability is well established within the literature (Chen et al., 2023; Hoyle et al., 2021). As the NDIS was established to improve the lives of Australians with disability by increasing their access to necessary supports further research is required to understand what specific changes are required within the NDIA to ensure that these families are not placed under any further unnecessary stress.

The second research question aimed to understand how unmet support needs differed by specific child characteristics. Findings revealed that older children had significantly higher rates of unmet needs when compared to younger children. The NDIA place emphasis on their early childhood approach targeting specialised supports towards infants and young children (nine years and younger) to promote child development, and child and family wellbeing and community engagement (NDIS, 2024). Interestingly, within the present study children aged nine and above experienced significantly higher unmet support needs when compared to the younger years. This may suggest that the NDIA place a higher value on providing participants with early childhood intervention, rather than the supports required for an individual to function optimally across the lifespan. Into adolescence and adulthood individuals with disabilities are faced with many complexities including increasing responsibilities and desire for independence (Joly, 2015). As such, the NDIA should look to

better understand the needs of these young people beyond the services that are provided as part of early intervention to ensure that they are supported to reach their full potential across their whole life.

Another finding within this study was that children with higher support needs, as well as autistic children and children with intellectual disability or a learning disability were more likely to report unmet needs. As previously stated, it appears that the success families experience gaining funds and accessing services from the NDIS directly related to their capacity to advocate for their children (Gavidia-Payne, 2020; Rangasinghe et al., 2017; Russo et al., 2021; Smethurst et al., 2020). Further, previous literature indicates that children of parents with disability may experience greater challenges accessing the necessary supports for their children. Autism, intellectual disability and learning disabilities have all been found to have a genetic link (Autism Awareness Australia, n.d.; Council for Intellectual Disability, 2018; Foster et al., 2015) meaning that there is an increased likelihood that their parents will also have a disability. Given the complexity of these families, further research is required to understand what assistances and resources are required from the NDIA to ensure that these families are afforded with equitable access to the supports their child requires.

For children with high support needs, these individuals often require a higher quantity of complex supports. For example, within a qualitative longitudinal study exploring the experiences of parents of children with cerebral palsy with high support needs several parents described that for their child to participate in any daily activity they required support from either equipment and/or a support person (O'Neill et al., 2024). Lack of disability specific knowledge of the NDIA staff charged with deciding what supports are approved by the NDIS has frequently been cited as a barrier within the literature (Gavidia-Payne, 2020; O'Neill et al., 2024; Ranasinghe et al., 2017; Tracey et al., 2018). To address this continued concern, the NDIA should look to evaluate the qualifications and training of the NDIA staff responsible

for supporting families to access services and supports to ensure they have a clear understanding of what is ‘reasonable and necessary’ for these individuals.

The third research question looked to understand the environmental factors that may influence the support provided to children with disability. Consistent with previous literature (e.g., Gavidia-Payne, 2020; Ranasinghe et al., 2017; Russo et al., 2021; Tracey et al., 2018), findings revealed that low socio-economic status, having a parent with a disability, and living within a regional or remote location were associated with higher levels of unmet needs. Interestingly, children living within a two-parent household were found to have lower levels of unmet needs. As previously described, a consistent theme within all literature exploring the experience of parents accessing supports for their children with disability is the physical, cognitive and emotional toll it takes for them to act as advocates to ‘fight’ for the supports they believe their child requires (e.g., Gavidia-Payne, 2020; O’Neill et al., 2024; Ranasinghe et al., 2017; Russo et al., 2021; Tracey et al., 2018). It is understandable that parents who share the care taking responsibility of their child may have additional capacity to partake in this advocacy role when compared to single parents who are left to take on all caretaking responsibilities on their own. These findings emphasise the need for change within the NDIA to ensure that parents and caregivers of children with disability are not met with added burden. These changes will assist to ensure that the supports provided to children with disability are distributed equitably based on the individuals need, rather than the responsibility and pressure placed on the capacity of the parents to act as their child’s advocates.

Strengths and limitations

As the first dedicated survey aiming to understand the needs and experiences of children with disabilities and their families in Australia, the current article makes an important contribution to an area of research that has been exclusively qualitative to date. Notably, as the NDIS

transitions to a system of eligibility based on functional limitations rather than diagnosis (NDIS review 2023) data that enables comparison of the experiences of children with different types and levels of functional impairment will be increasingly important – to our knowledge no previous study uses a validated measure of functional limitations (Cappa et al. 2018; Loeb et al. 2018) to investigate equitable support for children with disabilities. Nor do previous studies offer systematic evidence of the patterns of inequitable access to support demonstrated in the current study. Nonetheless, there are important limitations which should be borne in mind when interpreting our findings and should be remedied in future research. Notably, the Better Support for Kids with Disabilities survey is not a probability sample, representing a significant barrier to generalisation. Given the lack of data for a comparable reference population, it is difficult to ascertain the extent to which survey respondents differ from the general population, although it seems clear that more highly educated parents are overrepresented in our data. As unmet needs are strongly related to family socioeconomic position, this suggests that our data are likely to understate the true extent of unmet need in the population. Ideally, future survey research would be based on a representative sampling frame, but this does not exist at present, meaning that it would be necessary to first screen households for the presence of children with disabilities. The high cost of such a strategy means that alternative approaches to recruitment similar to the current study are likely to have continuing value in survey-based research on children with disabilities. Our measure of unmet needs was also constrained by considerations of respondent burden, and does not provide evidence of the frequency or impact of unmet needs – it is, rather, a measure of the *breadth* of unmet needs.

Conclusion

Despite major changes in models of disability support in Australia over the past decade, children with disabilities continue to experience high levels of unmet needs for support.

Moreover, unmet needs for support are unequally distributed, with higher levels of unmet needs among older children, those with more significant functional limitations, and those from families that are poorer, live in rural or remote areas, and have single parents and/or include adults with disabilities. There is a pressing need for changes to models of disability support to provide better and more equitable support.

References

Autism Awareness Australia. (n.d). Causes of autism. [Accessed on 1st December, 2024]

Available: <https://www.autismawareness.com.au/navigating-autism/causes-of-autism>

Cappa, C., Mont, D., Loeb, M., Misunas, C., Madans, J., Comic, T., & de Castro, F. (2018) The development and testing of a module on child functioning for identifying children with disabilities on surveys. III: Field testing, *Disability and Health Journal*, 11: 510-518.

Chen, C., Bailey, C., Baikie, G., Dalziel, K. & Hua, X. (2023). Parents of children with disability: Mental health outcomes and utilisation of mental health services. *Disability and Health Journal*, 16, 1-7. <https://doi.org/10.1016/j.dhjo.2023.101506>.

Council for Intellectual Disability. (2018). Causes of intellectual disability and health care.

[Accessed on 1st December, 2024] Available: [https://cid.org.au/wp-](https://cid.org.au/wp-content/uploads/2019/10/15-Causes-of-intellectual-disability-and-health-care.pdf)

[content/uploads/2019/10/15-Causes-of-intellectual-disability-and-health-care.pdf](https://cid.org.au/wp-content/uploads/2019/10/15-Causes-of-intellectual-disability-and-health-care.pdf)

Devine, A., Dickson, H., Rangi, M., Huska, M., Disney, G., Yang, Y., Barney, J., Kavanagh, A., Bonyhady, B., Deane, K. & McAllister, A. (2021). ‘Nearly gave up on it to be honest’: Utilisation of individualised budgets for people with psychosocial disability within the Australia’s National Disability Insurance Scheme, *Soc Policy Adm*, 56, 1056-1073.

<https://doi.org/10.1111/spol.12838>.

Foster, A., Titheradge, H. & Morton, J. (2015). Genetics of learning disability, *Paediatrics and Child Health*, 25(10), 450-457. <https://doi.org/10.1016/j.paed.2015.06.005>

Gavidia-Payne, S. (2020). Implementation of Australia’s National Disability Insurance Scheme: Experiences of families with young children with disabilities, *Infants and Young Children*, 33(3), 184-194. <https://doi.org/10.1097/IYC.000000000000169>

Hoyle, J., Laditka, J. & Laditka, S. (2021). Mental health risks of parents of children with developmental disabilities: A nationally representative study in the United States. *Disability and Health Journal*, 14, 1-8. <https://doi.org/10.1016/j.dhjo.2020.101020>.

Joly, E. Transition to adulthood for young people with people complexity: An integrative literature review. *Journal of Pediatric Nursing*, 30(5). e91-e103.
<https://doi.org/10.1016/j.pedn.2015.05.016>

Loeb, M., Mont, D., Cappa, C., De Palma, E., Madans, J., & Crialesi, R. (2018) The development and testing of a module on child functioning for identifying children with disabilities on surveys. I: Background, *Disability and Health Journal*, 11: 495-501.

Moore, T., Foster, J. & Bull, K. (2019). Supporting parental choice: The impact of a funding model. S. Acar, H. Hix-Small, T. McLaughlin (Eds.), *International Perspectives on Early Intervention*. Young Exceptional Children Monograph Series, No. 18, Division of Early Childhood, Council for Exceptional Children, Arlington, Virginia

National Disability Insurance Scheme. (n.d.). A timeline of the national Disability Insurance Agency. Accessed on 1st December, 2024] Available: <https://www.ndis.gov.au/about-us/history-ndis#:~:text=The%20NDIS%20was%20legislated%20in,supports%20for%20the%20first%20time.>

National Disability Insurance Scheme. (2024). Explore data.
<https://dataresearch.ndis.gov.au/explore-data>

National Disability Insurance Scheme. (2024). The early childhood approach for children younger than 9. [Accessed on 1st December, 2024] Available:
<https://www.ndis.gov.au/understanding/families-and-carers/early-childhood-approach-children-younger-9>

O'Neill, M, Bourke-Taylor, H., Bhojti, A. & Cotter, C. (2024). The experiences of families of children with cerebral palsy and complex disability after three years accessing the National Disability Insurance Scheme, *Australian Occupational Therapy Journal*, 00, 1-15,

<https://doi.org/10.1111.1440-1630.12973>.

Pye, K., Le, Ha, Iacono, T. & Gold, L. (2024). Utilization of early therapeutic supports by autistic preschoolers in Australia: A cross-sectional study following implementation of the National Disability Insurance Scheme, *International Society for Autism Research*, 00, 1-13.

<https://doi.org/10.1002/aur.3255>.

Ranasinghe, T., Jeyaseelan, D., White, D. & Russo, R. (2017). Parents' experiences in registering with and accessing funding under the National Disability Insurance Scheme for early intervention services for children with developmental disabilities, *Journal of Paediatrics and Child Health*, 53, 26-32. <https://doi.org/10.1111/jpc.13312>.

Russo, F., Brownlow, C. & Machin, T. (2021). Parental experiences of engaging with the National Disability Insurance Scheme for their children: A systematic literature review, *Journal of Disability Policy Studies*, 32(2), 67-75.

<https://doi.org/10.1177/1044207320943607>

Smethurst, G., Bourke-Taylor, H., Cotter, C. & Beauchamp, F. (2020) Controlled choice, not choice and control: Families' reflections after one year using the National Disability Insurance Scheme. *Australian Occupational Therapy Journal*, 68, 205-216.

<https://doi.org/10.1111/1440-1630.12715>.

Tracey, D., Johnston, C., Papps, F. A., & Mahmic, S. (2018). How do parents acquire information to support their child with a disability and navigate individualised funding schemes? *Journal of Research in Special Educational Needs*, 18, 25–35.

Table 1: Sample summary statistics

| | N (%) or Mean (SD) | % Missing |
|--|--------------------|-----------|
| <u>Child characteristics and support</u> | | |
| Functional difficulties | | |
| <i>Sensory difficulty</i> | 25 (3.9) | 0.0 |
| <i>Physical difficulty</i> | 64 (10.2) | |
| <i>Communication difficulty</i> | 143 (22.2) | |
| <i>Cognitive difficulty</i> | 341 (53.0) | |
| <i>Social/behavioural difficulty</i> | 508 (78.9) | |
| <i>Mental health difficulty</i> | 308 (47.8) | |
| <i>Self-care difficulty</i> | 107 (16.6) | |
| Highest level of functional difficulty | | |
| <i>None</i> | 73 (11.3) | 0.0 |
| <i>Moderate</i> | 504 (78.3) | |
| <i>Severe</i> | 67 (10.4) | |
| Number of functional difficulties | | |
| | 2.3 (1.4) | |
| Diagnoses | | |
| <i>Autism</i> | 468 (72.7) | 0.0 |
| <i>ADHD</i> | 390 (60.6) | |
| <i>Intellectual disability</i> | 91 (14.1) | |
| <i>Mental health condition</i> | 268 (41.6) | |
| <i>Specific learning disability</i> | 112 (17.4) | |
| <i>Other developmental disability</i> | 53 (8.2) | |
| <i>Other disability/health condition</i> | 145 (31.4) | |
| Age | | |
| <i>2-4 years</i> | 78 (12.1) | 0.0 |
| <i>5-8 years</i> | 186 (28.9) | |
| <i>9-12 years</i> | 228 (35.4) | |
| <i>13-17 years</i> | 152 (23.6) | |
| <u>Parent, family, and area characteristics</u> | | |
| Education | | |
| <i>Less than degree</i> | 187 (30.8) | 5.7 |
| <i>Degree</i> | 420 (69.2) | |
| Partnership status | | |
| <i>Partnered</i> | 475 (78.4) | 5.9 |
| <i>Non-partnered</i> | 131 (21.6) | |
| Indigenous status | | |
| <i>Indigenous</i> | 16 (2.6) | 5.9 |
| <i>Non-Indigenous</i> | 590 (97.4) | |
| Language other than English at home | | |
| <i>Yes</i> | 68 (11.2) | 5.7 |
| <i>No</i> | 539 (88.8) | |
| Adult disability | | |
| <i>No</i> | 341 (56.1) | 5.6 |
| <i>Yes</i> | 267 (43.9) | |
| Log equivalised annual household income | | |
| | 11.0 (0.7) | 9.6 |
| Area advantage/disadvantage | | |
| | 0.0 (1) | 5.9 |
| Region | | |
| <i>Major city</i> | 455 (75.1) | 5.9 |
| <i>Inner regional</i> | 122 (20.1) | |
| <i>Outer regional/remote</i> | 29 (4.8) | |
| N | 644 | |

Table 2: Unmet support needs and child characteristics

| | | | | |
|--|-------------------|-------------------|-------------------|-------------------|
| Child age | | | | |
| 5-8 (vs. 2-4) | 1.20 (0.13) | 0.79 (0.10) | 0.94 (0.10) | 0.99 (0.11) |
| 9-12 (vs. 2-4) | 1.41** (0.15) | 0.97 (0.12) | 1.18 (0.12) | 1.04 (0.12) |
| 13-17 (vs. 2-4) | 1.50*** (0.17) | 1.06 (0.13) | 1.26* (0.13) | 1.02 (0.12) |
| Functional difficulty type | | | | |
| <i>Sensory difficulty</i> | | 1.11 (0.15) | | |
| <i>Physical difficulty</i> | | 0.99 (0.09) | | |
| <i>Communication difficulty</i> | | 1.07 (0.08) | | |
| <i>Cognitive difficulty</i> | | 1.31*** (0.09) | | |
| <i>Social/behavioural difficulty</i> | | 1.39** (0.14) | | |
| <i>Mental health difficulty</i> | | 1.26*** (0.08) | | |
| <i>Self-care difficulty</i> | | 1.40*** (0.11) | | |
| Functional difficulty summary | | | | |
| <i>Moderate functional difficulty (vs. none)</i> | | | 1.27 (0.19) | |
| <i>Severe functional difficulty (vs. none)</i> | | | 1.36 (0.25) | |
| <i>Count of functional difficulties</i> | | | 1.22*** (0.03) | |
| Disability type | | | | |
| <i>Autism</i> | | | | 1.52*** (0.12) |
| <i>Intellectual disability</i> | | | | 1.41*** (0.11) |
| <i>Other developmental disability</i> | | | | 1.14 (0.12) |
| <i>Anxiety/depression</i> | | | | 1.13 (0.07) |
| <i>ADHD</i> | | | | 1.12 (0.08) |
| <i>Specific learning disability</i> | | | | 1.28*** (0.09) |
| <i>Other disability/health cond.</i> | | | | 1.30*** (0.08) |
| Constant | 1.71 (0.16) | 1.25 (0.14) | 0.98 (0.15) | 1.18 (0.12) |
| N (644) | | | | |

Estimated incidence rate ratios based on $m = 20$ multiply imputed datasets. Robust standard errors in parentheses. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 3: Equity in unmet support needs

| | | | | | | |
|---|--------------------|----------------|-------------------|-------------------|------------------|-------------------|
| Socio-economic status | | | | | | |
| Household income ^(a) | 0.77*** (0.03) | | | | | 0.81*** (0.03) |
| Parent education <i>Degree (vs. no degree)</i> | 1.07 (0.06) | | | | | 1.11 (0.07) |
| Cultural background | | | | | | |
| <i>Indigenous (vs non-indigenous)</i> | | 0.96 (0.15) | | | | 0.90 (0.12) |
| <i>Other language (vs. English)</i> | | 0.98 (0.11) | | | | 1.02 (0.10) |
| Disability | | | | | | |
| <i>Adult disability (vs no adult disability)</i> | | | 1.41*** (0.08) | | | 1.29*** (0.07) |
| Partnership status | | | | | | |
| <i>Partnered (vs. no partner)</i> | | | | 0.74*** (0.04) | | 0.83** (0.05) |
| Area | | | | | | |
| <i>Inner regional (vs major cities)</i> | | | | | 1.25** (0.10) | 1.23** (0.09) |
| <i>Outer regional/remote (vs major cities)</i> | | | | | 1.38** (0.16) | 1.29* (0.14) |
| <i>Area advantage/disadvantage ^(b)</i> | | | | | 1.01 (0.03) | 1.06 (0.03) |
| Constant | 15.18*** (6.47) | 0.88 (0.13) | 0.81 (0.12) | 1.18 (0.19) | 0.83 (0.12) | 8.67*** (3.74) |
| N (644) | | | | | | |

Estimated incidence rate ratios based on $m = 20$ multiply imputed datasets. Robust standard errors in parentheses. * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. All models adjusted for child age, functional difficulties (highest level and count), and disability type (diagnosis). ^(a) Log equivalized gross annual household income. ^(b) Index of regional socioeconomic advantage and disadvantage (IRSAD).

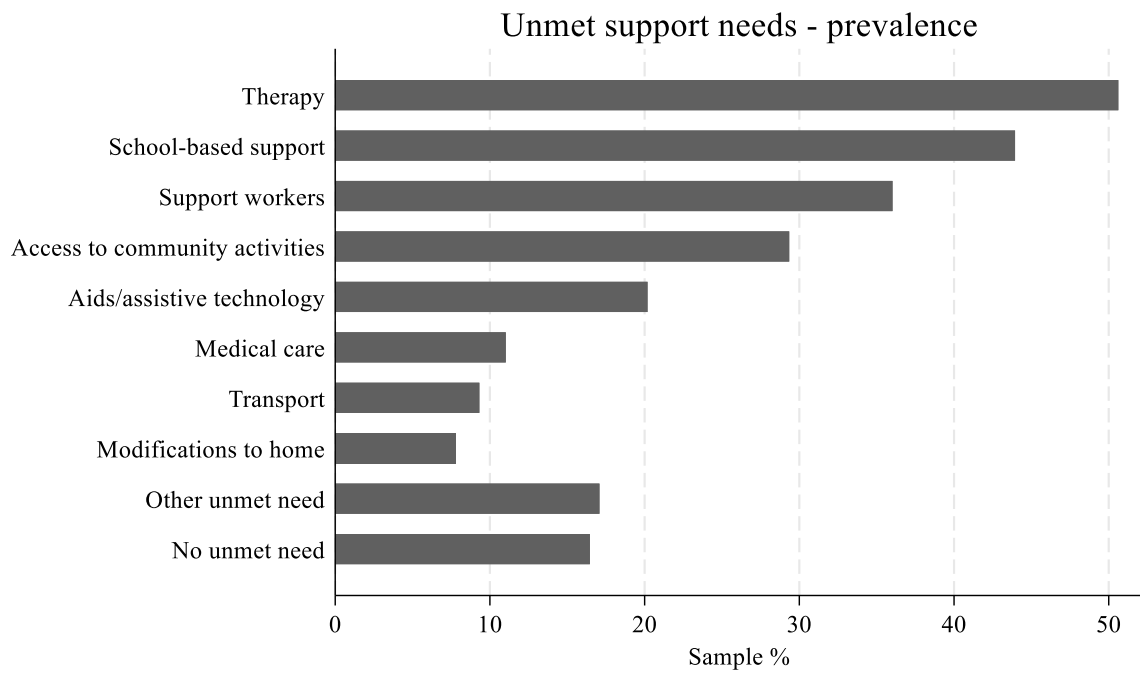
Figure 1: Prevalence of unmet support needs

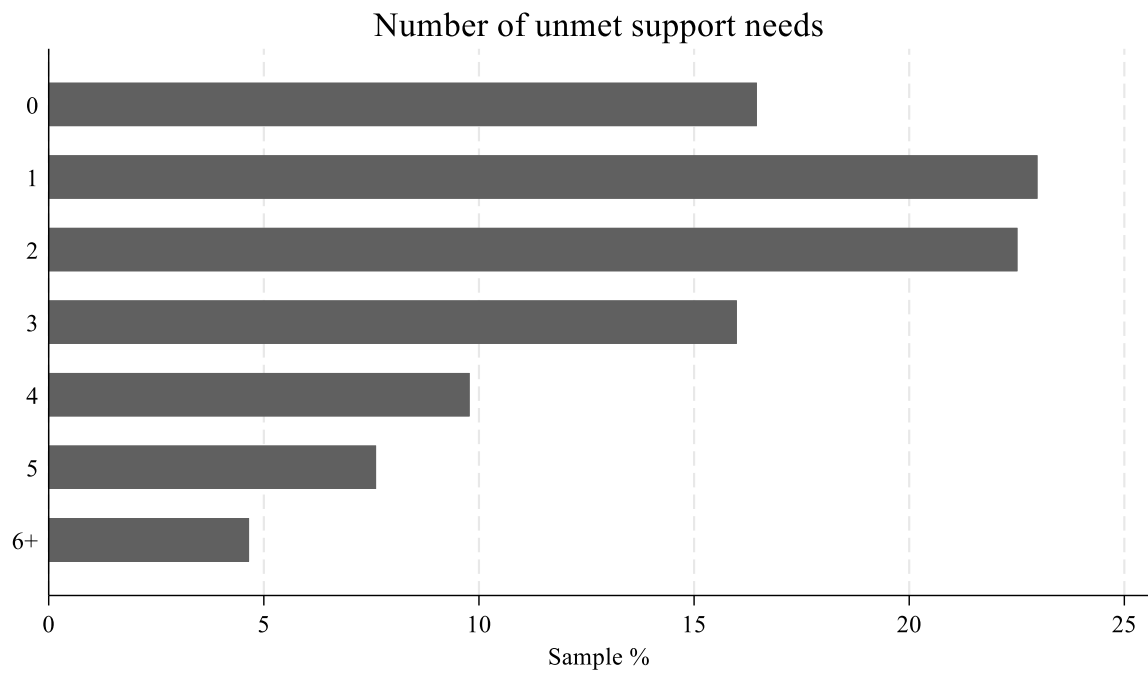
Figure 2: Number of unmet support needs

Figure 3: Reasons for unmet support needs