



YERRABI YURWANG
CHILD AND FAMILY ABORIGINAL
CORPORATION



Everything ADHD-related is a challenge



Supporting Families of Children with ADHD



December 2023



Everything ADHD-related is a challenge: Supporting Families of Children with ADHD ARACY

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Note about the report title:

'Everything ADHD related is a challenge' is a direct quote by one of the survey respondents answering a question about receiving a diagnosis, or being on the journey to receiving a diagnosis, of ADHD, and related challenges. Respondents were invited to type their open-text response.

Acknowledgements

A Village for Every Child and Yerrabi Yurwang would like to thank the families who participated in the ADHD survey. We deeply appreciate their valuable contribution and willingness to share and discuss their personal and lived experiences.

We would also like to thank members of Village's ADHD Action Group for their guidance and steering of the survey and comments on drafts of this report.

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1. Executive Summary

Background

The Deputy CEO of Yerrabi Yurwang Child and Family Aboriginal Corporation (Yerrabi Yurwang) tabled a paper to the A Village for Every Child's (Village) Leadership Group concerning the impact of Attention Deficit Hyperactivity Disorder (ADHD) on Aboriginal children, their families, and their life outcomes. In response, the ADHD Action Group (the Action Group) was formed. The Group brings together experts from across government and non-government sectors to investigate the issue further, with the aim of leveraging available resources within the current service and support system to creatively address whole of family support needs. Any resulting actions would also focus on understanding and supporting local Aboriginal families' experience and needs, as well as forming a whole of community response.

The Action Group administered a survey in late 2023 to better understand the needs of families in the ACT with ADHD. The survey results highlighted the challenging journey experienced by families as they navigate ADHD supports and diagnosis in Canberra.

ARACY was engaged by the Action Group to undertake an analysis of, and report on, the survey results. The Action Group will use this report to guide a coordinated approach to working with ACT families with ADHD to provide appropriate and practical responses.

This report provides findings across all survey responses and does not separate responses provided by families identifying as Aboriginal. Data from families identifying as Aboriginal has been provided to Yerrabi Yurwang to determine how to specifically address issues raised by these families.



Survey findings

The survey, *Understanding the needs of families with ADHD*, was conducted between September and December 2023. Respondents generously shared their stories of what has challenged them most in their situations, as well as what has helped most during the challenging times.

Key themes reflected in the survey were also reflected in the ACT Education Directorate's recent Community Conversation report.¹ This report helped to inform Inclusive Education: A Disability Inclusion Strategy for ACT Public Schools 2024-2034. The themes are also consistent with recommendations put forward by national inquiries into the disability sector and ADHD specifically.

What emerged from these stories forms three key considerations for next steps in responding to the needs of families of children with ADHD in the ACT.

- ✓ A more consistent and coordinated approach to diagnosis, with a clear pathway that helps each family understand their journey to diagnosis and supports, both medical and non-medical.
- ✓ A centralised location for reliable information and resources that can be easily accessed and shared among individuals and their supports. This is critical to ensure that people obtain reliable, accurate and comprehensive information about ADHD, and where they can find support. Support from peers and social media were common forms of support identified in the survey, but ensuring reliability and accuracy of this information is vital.
- ✓ Face to face care and support that considers the whole family, taking into consideration the intergenerational impacts of ADHD, and the high prevalence of co-existing conditions (diagnosed or otherwise).

Among the many support needs of the ADHD community highlighted in the survey, first and foremost was increased affordability and accessibility of health professionals, and difficulty accessing NDIS funding. While these are not issues that can be easily addressed or tackled by the governments alone, there is a strong need for widespread awareness raising and community education, alongside conversation and discussion, to ensure families do not experience (further) discrimination, isolation, shame or worse, because of their challenging situations.

¹ A Community conversation - Education
<https://www.education.act.gov.au/our-priorities/inclusive-education-a-disability-inclusion-strategy/a-community-conversation>

The survey findings also provide suggestions for programmatic responses, including:

- ✓ For children: a strong need of support for programs with practical strategies, and social/support groups, as well as additional support needs in the education system, such as clear information about available staff to talk to in relation to a child's ADHD needs, and ADHD education for all educators/teachers.
- ✓ For parents and other family members: an emphatic need for support for improvements such as information sessions, education for the whole family, and social/support groups, as well as highly sought after supports, including health sector support, awareness/resources, and family/home support.

Responding to the survey findings

Yerrabi Yurwang and the ADHD Action Group

Yerrabi Yurwang engaged with the local Aboriginal community on their experiences of ADHD through its current community engagement model. Conversations were had with members of the Yerrabi Women's Group and the survey was circulated to their networks. Yerrabi Yurwang will lead further community participation activities to respond to the survey findings.

The Action Group's diverse membership includes ACT Government officials who are involved in implementing strategies that impact on families with ADHD. The next steps for the ADHD Action Group will be to bring together community members who will use the report findings and their expertise to consult on responses. This work will help ensure that practical information, resources, and services to support families meets their expressed needs and helps to improve their lived experiences of ADHD within the ACT context.

More information about Yerrabi Yurwang and Village and how these partners have facilitated the survey through the Action Group is provided in Appendix One.

2. Context

Support for children and families with ADHD is a critical issue for a growing number of families across the ACT and Australia. It is important to recognise that ADHD is a cross-sector and cross-system issue. As a place-based systems change initiative, Village and its partners seek to understand the experience of ACT families, through their lens, as these systems interact and affect their day to day lives. Accordingly, policy and program developments across both levels of government and relevant sectors need to be considered.

The ADHD Action Group recognises that both Commonwealth and the ACT Governments are currently undertaking several related community consultation or inquiry processes that will examine and seek to improve the experience of families with ADHD. At the time of writing, these processes include:

- ✓ Inclusive Education: A Disability Inclusion Strategy for ACT Public Schools 2024-2034 and its accompanying first action plan.² The ten-year strategy was released in December 2023, and is part of the Future of Education strategy.
- ✓ The Commonwealth Senate Inquiry: Assessment and support services for people with ADHD, whose report was released in November 2023.³
- ✓ The recommendations from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, released in September 2023.⁴

More information about the Inclusive Education: A Disability Inclusion Strategy for ACT Public Schools 2024-2034 and the findings from the Senate Inquiry are included in Appendix Two.

² Inclusive Education: A Disability Inclusion Strategy for ACT Public Schools 2024-2034 - Education
<https://www.education.act.gov.au/our-priorities/inclusive-education-a-disability-inclusion-strategy>

³ Assessment and support services for people with ADHD - Parliament of Australia
https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/ADHD/Report

⁴ Final Report | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability
<https://disability.royalcommission.gov.au/publications/final-report>

3. The Survey: Understanding the needs of families with ADHD

Members of the Action Group designed the survey and disseminated it to families with experience of ADHD via their networks. A copy of the survey is provided in Appendix Three.

Yerrabi Yurwang focused its engagement with the local Aboriginal and Torres Strait Islander community through its existing community engagement activities and networks. Village utilised its partners and their networks, including government and non-government organisations, ACT Public Schools and Early Childhood Education and Care services, ADDACT and Village social media and newsletter.

Between September and December 2023, the survey received a total of 103 responses. Respondents included parents and carers of children with an ADHD diagnosis or with undiagnosed ADHD.

Findings

Respondent Characteristics

The results showed:

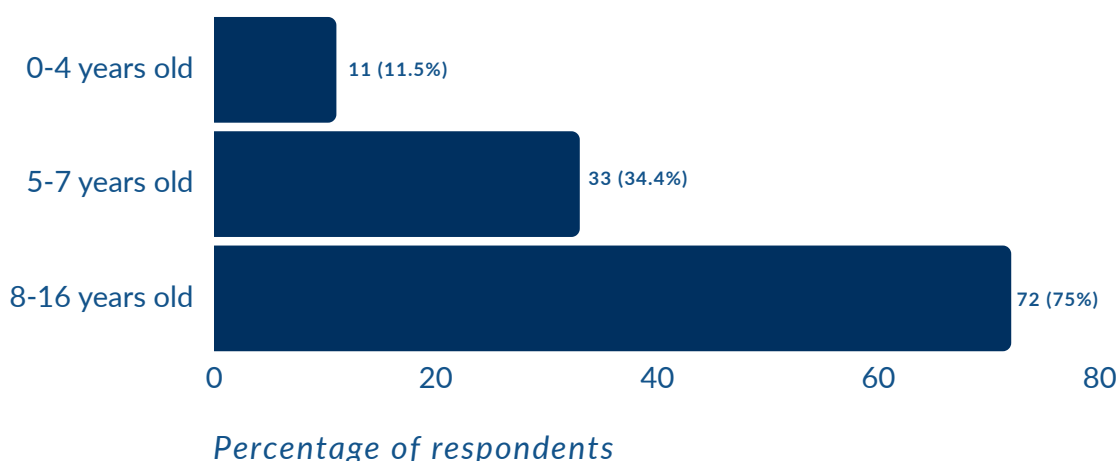
- ✓ Culturally, the majority of respondents identified as either Australian (77%) or Aboriginal (19%).
- ✓ Over three quarters (76.8%) of family members have a diagnosis, with the others being either in the process of getting a diagnosis (11.1%) or not yet diagnosed or not on the diagnostic path (12.1%).
- ✓ Reported levels of severity were either moderate (approximately half, 49%), or severe (38%).
- ✓ The hereditary nature of ADHD was highlighted, with over half (61 respondents, or 59%) reporting more than one family member with ADHD, and one fifth of the respondents themselves (20 respondents, or 19%) reporting they also have ADHD (suspected or diagnosed). This heritability has a range of ramifications for families, including that some families must make difficult decisions about care in their household.



Almost two fifths of the respondents (39%) reported having a co-existing condition, highlighting the difficulty faced by families when trying to understand what the issues are, and therefore which avenue is best to take, and where to start; this challenge is exacerbated in cases where parents/carers themselves have ADHD.

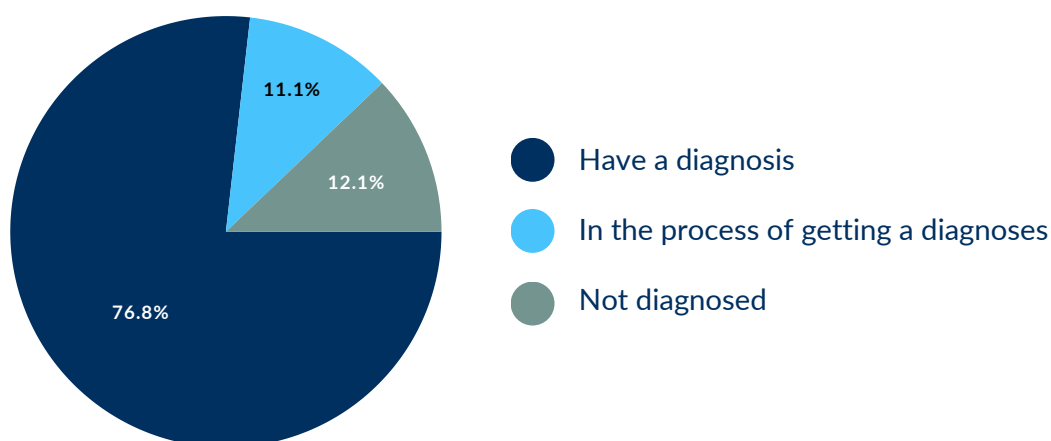
► Diagnosis and Heredity

Chart 1: Age of the person/s in your family with suspected or diagnosed ADHD (96 responses)



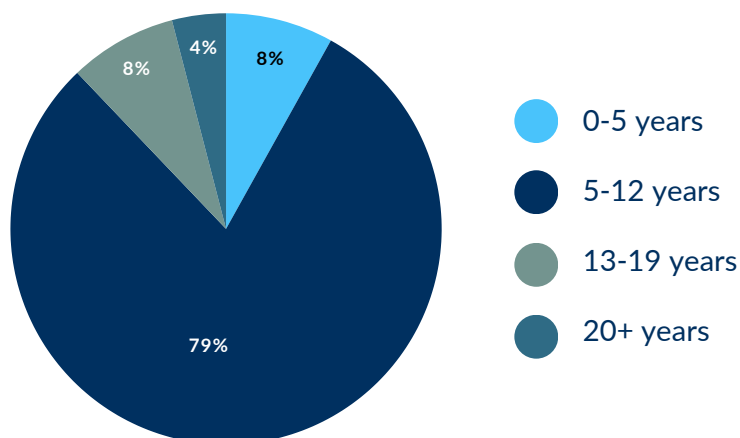
It is evident from the responses that childhood diagnosis (or suspected diagnosis) of ADHD becomes clearer as children age, with three-quarters of respondents (75%) reporting a family member being in the oldest age group (8-16 years); one in three (35%) aged from 5-7 years; and the minority (12%) in the youngest group (0-4).

Chart 2: Does your family member have a diagnosis of ADHD or are they in the process of getting one? (96 responses)



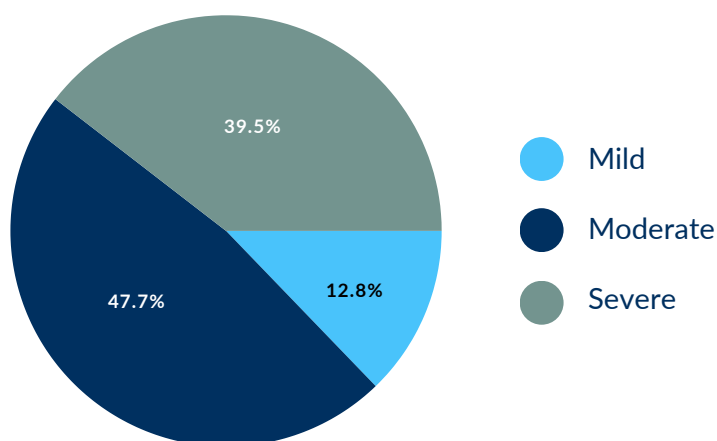
Among respondents, approximately three-quarters (77%) reported their child/family member as having a diagnosis, with the remaining being either in the process of getting a diagnosis or not diagnosed.

Chart 3: Age of diagnosis



While a wide range of ages were reported for when a diagnosis of ADHD was received, the most common age group was 5-12 years. The most commonly reported age for diagnosis was six years, reported by approximately one third of respondents (35%).

Chart 4: Level of severity (86 responses)



Severity was self-reported. Among respondents whose family members have a diagnosis of ADHD, the level of severity was typically moderate (approximately half, 49%), or severe (38%). Just over one in 10 (12%) have a mild level of severity.

Hereditary

While no single cause of ADHD is known at this point, research supports that ADHD is an interaction of genetic, social, and environmental factors - and is 'highly heritable' (estimated at between 70 and 80 per cent).⁵

The hereditary nature of ADHD was highlighted in the survey results, with over half of respondents (61 respondents, or 59%) reporting more than one family member with ADHD. Approximately one fifth of families (20 respondents, or 19%) were families with parents/carers also reporting suspected or diagnosed ADHD.

Co-existing conditions

Approximately 39% of survey respondents reported significant levels of co-existing disorders/conditions in their ADHD family members. These included neurodevelopmental disorders, mental health disorders, and other medical conditions, which respondents were invited to specify in an open text response.

Neurodevelopmental disorders:

- ✓ ASD (Autism Spectrum Disorder) level 1, level 2, and level 3
- ✓ Suspected dyspraxia
- ✓ Dyslexia
- ✓ Spatial processing disorder
- ✓ Developmental language disorder
- ✓ Language delay
- ✓ PDA (Potentially Pathological Demand Avoidance)
- ✓ Sensory Processing Disorder
- ✓ Auditory Processing Disorder
- ✓ Global Development Delay



⁵ Retrieved from: Senate Community Affairs References Committee (2023). Footnote 15: Australian ADHD Professionals Association, *Australian Evidence-Based Clinical Practice Guideline For Attention Deficit Hyperactivity Disorder (Clinical practice guideline)*, p. 65; WA Department of Health, Submission 23, p. 2; Deloitte Access Economics, *The social and economic costs of ADHD in Australia*, (July 2019), pp. ii and 7-8.

Mental health:

- ✓ Anxiety
- ✓ Depression
- ✓ PTSD (Post-Traumatic Stress Disorder)
- ✓ Borderline Personality Disorders
- ✓ Conduct Disorder
- ✓ ODD (Oppositional Defiant Disorder)
- ✓ OCD (Obsessive-Compulsive Disorder)
- ✓ Conduct disorder

Other medical conditions:

- ✓ Cerebral Palsy
- ✓ Type 1 Diabetes (T1D)
- ✓ Mild intellectual disorder
- ✓ Ehlers-Danlos syndrome

The survey findings echo the Senate Inquiry evidence from the ADHD Foundation that ADHD is often coupled with other suspected or diagnosed conditions. According to the ADHD Foundation, it is common to have co-existing conditions with ADHD – such as anxiety, depression, learning difficulties, autistic spectrum; and unfortunately, some people are treated for their presenting problem, overlooking the underlying ADHD.⁶ Further, in their submission to the Senate inquiry, the Foundation notes that ADHD can lead to mental health issues.⁷

⁶ Retrieved from: <https://adhd.foundation.org.au/understanding-adhd>

⁷ Retrieved from: Senate Community Affairs References Committee (2023). Footnote 74: ADHD Foundation, Submission 12, p. 9.

The experience of living with ADHD

The survey canvased the lived experience of families of children with ADHD. Respondents generously shared their stories of what has challenged them most in their situations, as well as what has helped most during the challenging times. A selection of quotes from the survey illustrating this lived experience is included in Appendix Four.

► Most challenging part of living with ADHD in your family

85% of families gave details about the most challenging aspects of living with ADHD in their family. The challenges were often multidimensional and layered, and the significant need for extensive support is palpable. Key themes included emotional, social, and behavioural challenges, along with key stress triggers and support challenges.

- ✓ **Emotional challenges** – carer burnout; exhaustion, stress, emotional dysregulation, feeling misunderstood; feelings of shame.
- ✓ **Social challenges** – judgement from other parents and family members; the desire for people to know and understand your child; people thinking they know your child (but only the ‘medicated’ version); a lack of understanding of the impacts of ADHD.
- ✓ **Behavioural challenges** – managing differing needs of offspring with ADHD and the conflicts between siblings; understanding moods and learning styles; dealing with sleeping and diet/eating challenges; impulsivity leading to violent outbursts toward younger siblings; risk taking behaviours; sensory overload; helping child have successful relationships; managing mood swings, meltdowns, explosive outbursts; inattentiveness; constant repetition; lack of caution of danger; extremes in day-to-day capacities; extreme disorganisation and mess; hyperactivity; keeping child/ren safe; medication adjustments over time.
- ✓ **Stress triggers** – sending a child to camp; social outings; family participation; identifying which school will be least/less traumatising; discrimination from educational bodies.
- ✓ **Support challenges** – lack of ACT-centric supports; no NDIS recognition of ADHD; cost/affordability of paediatricians and other professionals; parenting; support for parents/carers of children with ADHD; schools not being able to comprehensively support students with ADHD; getting tests and diagnosis; minimal and confusing information.

Challenges receiving a diagnosis

Sixty five families (63%) gave details about the challenges of receiving a diagnosis or being on the journey to receive a diagnosis. In line with findings above, 40% of these (26 families) were either unable to state what had helped in their situation (response left blank) or reported that 'nothing' had been helpful.

Some referred to having tenacity and not giving up as the factor that helped to achieve the diagnosis, highlighting the challenging barriers to achieve diagnosis:

*"My daughter not giving up"; "Don't take no for answer"; "I never took no for an answer"; "Perseverance"; "Had to be patient."
(Survey respondents)*

*"Ultimately, what helped most was support from family, friends and schools, and having access to medical professionals and the ability to pay for required appointments."
(Survey respondent)*

*"We already had a paediatrician, so we are quite lucky and we do get some rebate back from her. There is no rebate from a private diagnosis which is horrendous."
(Survey respondent)*

*"The bank of mum and dad. As no funding is available and public system is a joke."
(Survey respondent)*



Challenges when multiple family members have ADHD and co-existing conditions

The prevalence of co-existing conditions/disorders exacerbates the difficulty faced by families when trying to understand what the issues are, and therefore know which avenue is best to take and where to start. This challenge is increased in cases where parents/carers themselves have ADHD, potentially with other co-existing conditions/disorders.

What has helped? What would help?

The survey asked respondents about what has helped their family during their most challenging times living with ADHD. Importantly, among the 85% of respondents (representing 87 families) who described the most challenging aspects, approximately one third of these (31%, 27 families) were either unable to state what had helped in their situation (response left blank) or reported that 'nothing' had helped. Given the recognised lack of available support for families with ADHD in the ACT, this is not surprising but still concerning.

"Nothing. We are struggling." - (Survey respondent)

"Nothing still going through it no support has been offered." - (Survey respondent)

"Nothing. We have no family support." - (Survey respondent)



Among the remaining two thirds of respondents (69%, 60 families) who stated what had helped in their situation, the most frequently reported supports included medication (14 respondents), support and guidance from friends 'in the know' (7 respondents), and being able to access professional help, medical or otherwise, e.g. EACH program (6 respondents).

Overall, supports included:

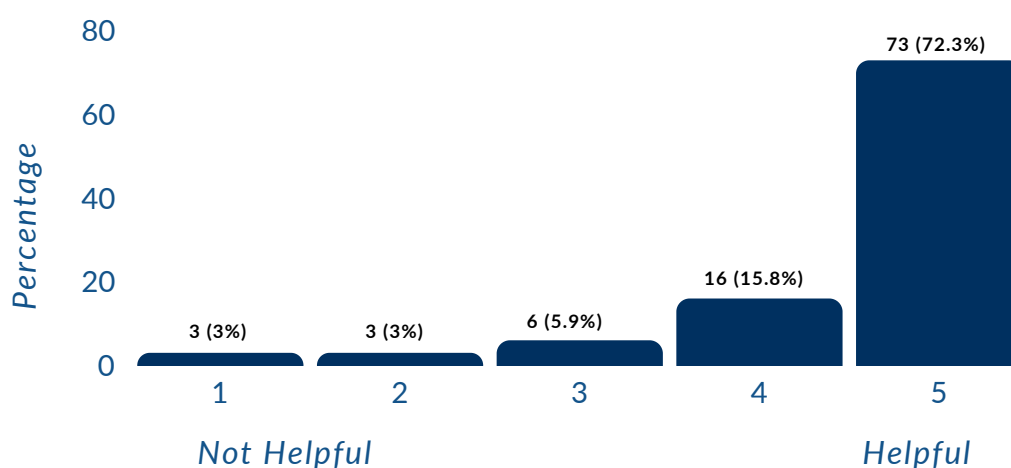
- ✓ medication
- ✓ support from family, friends and partners
- ✓ talking to friends in similar situations
- ✓ where costs allow, private providers such as OT's, psychologists, paediatricians
- ✓ supportive schoolteacher and executive teaching staff
- ✓ funding from education
- ✓ Medicare mental health plans
- ✓ online seminars (mainly from US)
- ✓ changes in principal/school staff
- ✓ talking to EACH/ EACH program
- ✓ relaxing (own) expectations
- ✓ self-education about child's neurotype and how to be an advocate

- ✓ creating a routine
- ✓ creating rules
- ✓ self care, including staying calm, the gym, mindfulness/meditation
- ✓ dietary support
- ✓ pathways to preschool
- ✓ reading extensively online and understanding neurodivergence and the need for advocacy
- ✓ University of Canberra's Health Hub
- ✓ Dr Russell A.Barkley
- ✓ ADDitude Magazine
- ✓ seeing a happy child/ren
- ✓ support groups

► Support needs of children

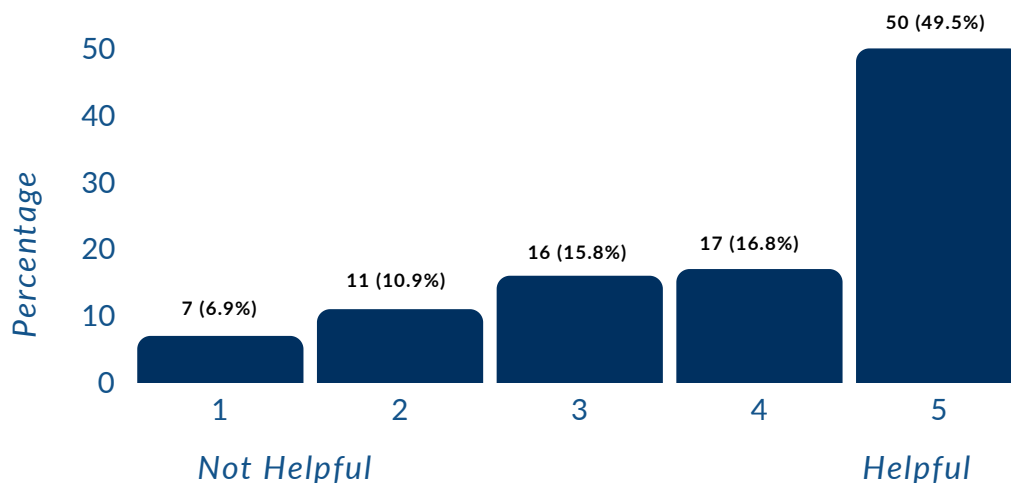
The survey asked parents/carers to rate two options for specifically child-focussed supports: programs with practical strategies; and social/support groups. The following charts highlight the significant need for improvements in this area. The questions asked respondents to rate from 1 (not helpful) to 5 (extremely helpful).

Chart 5: Would programs for children to provide them with strategies to learn how to self-manage feelings and behaviours be helpful? (101 responses)



Almost three quarters of respondents (72%) rated social/support groups and programs that include practical strategies for children 'extremely helpful' (5), and close to nine tenths (90%) of the respondents rated this suggestion 4 or 5 on the scale.

Chart 6: Would a social/support group be helpful? (101 responses)



The support indicated for social/support groups for children was less pronounced, however half of the survey respondents (50%) rated the suggestion 'extremely helpful' (5), and a further smaller group (17%) thought this would be 'helpful' (4).

"There is very little support - anything for emotional regulation would be an improvement. Our children have been in wait lists for community programs but there is no space." - (Survey respondent)

"Children with ADHD need better support to understand how they are different and how they learn best." - (Survey respondent)

"A social support group would only be useful if it was neuroaffirming; helping individuals make friends and socialise with their neurotribe to promote self-identity and a sense of belonging rather than pushing neuronormative standards on neurodivergent individuals so they mask and increase their risk of suicidality." - (Survey respondent)

”

► Support needs for parents and other family members

The survey invited respondents to make recommendations to improve ADHD support systems in the ACT. These results provide an excellent starting point for understanding what families find helpful and will be critical in shaping the consultation process to design responses.

The following charts highlight the emphatic support received for prompted improvements in relation to support needs for parents and other family members, such as information sessions, education for the whole family, and social/support groups.

While just over half of people who responded to this section in the survey (consistently 55%) rated each of the three suggested supports 'extremely helpful' (5 on a scale of 1 to 5), between 66% and 83% of respondents rated the three suggested supports 'helpful' or 'extremely helpful' (4 or 5). While respondents did not rate social/support groups (66% rating 4 or 5) as highly as information sessions and education for the whole family (83% and 74% respectively rating 4 or 5), they were still strongly supported.

Chart 7: Would information sessions about understanding ADHD, services and supports, referral pathways and/or access to professionals be helpful? (101 responses)

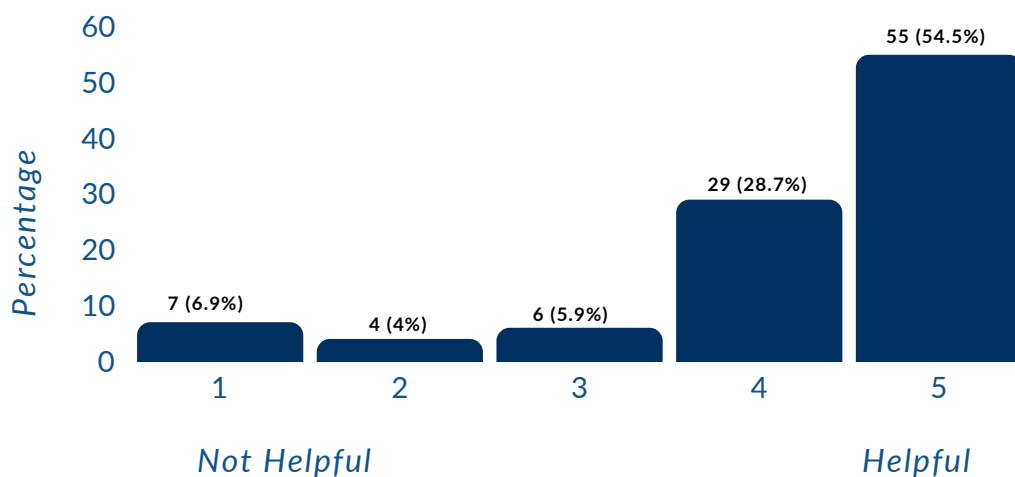


Chart 8: Would education for the whole family, focusing on specific needs of families/children with undiagnosed or diagnosed ADHD be helpful? (101 responses)

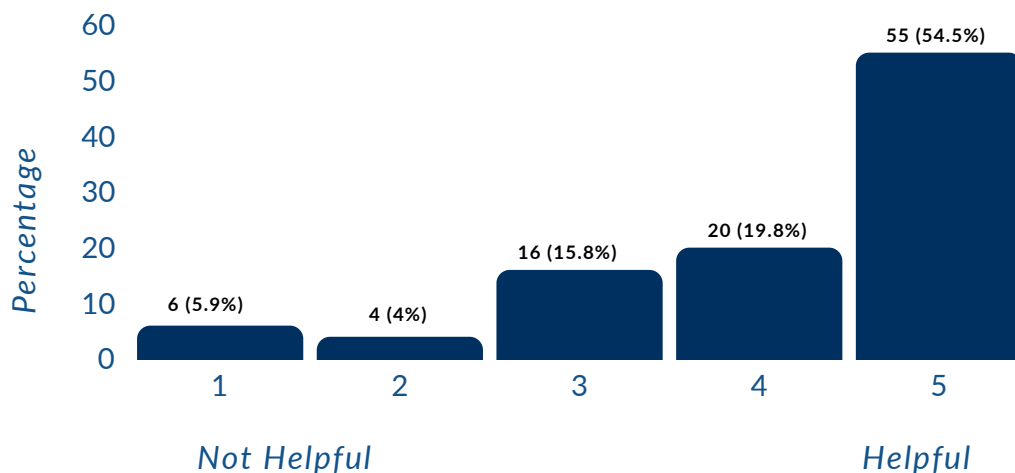
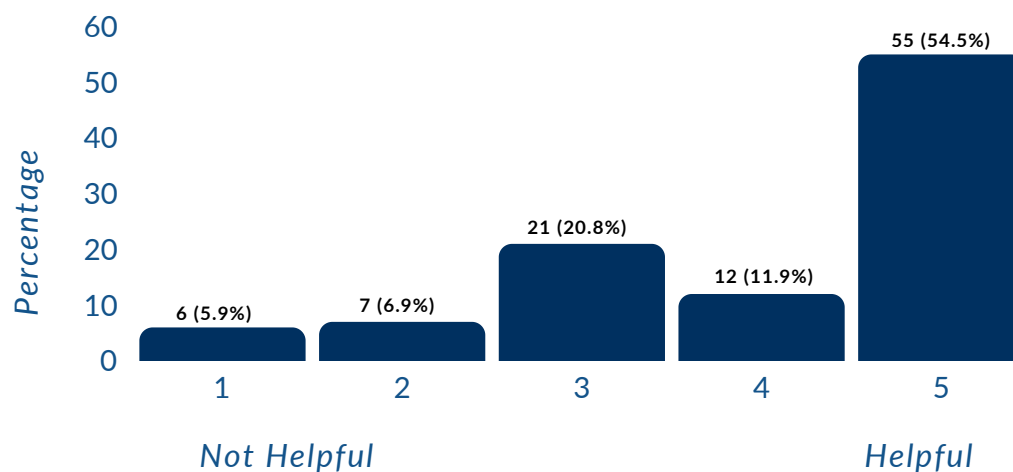


Chart 9: Would social/support groups be helpful? (101 responses)



Respondents also stated what would have helped their situation (desired support), with improved affordability and accessibility of professionals emerging as a clear and fundamental need.

Suggestions for support included:

- ✓ a clear/solid path and knowing where to go
- ✓ getting a diagnosis and affordability of diagnosis
- ✓ knowing how to start the process
- ✓ NDIS with funding
- ✓ peer support from those with lived experience, particularly for those with recent diagnoses
- ✓ family support
- ✓ empathy
- ✓ parenting courses designed specifically for how to parent neurodivergent (ND) kids if you are an ND parent
- ✓ social change
- ✓ improved availability of professionals and reduced waiting times to see professionals
- ✓ financial assistance to help access all support for family members with ADHD
- ✓ school recognition of challenges

Respondents also provided suggestions for additional highly sought after supports, which have been grouped into several key themes, including health sector support; awareness/resources; and family/home support.

Health sector supports:

- ✓ a clearer assessment pathway for diagnosis, particularly for low-income families
- ✓ affordability and timely access to health professionals for diagnosis and treatment – paediatricians, psychologists, Allied Health Professionals (e.g. OTs and speech therapists specialising in ADHD), counselling
- ✓ improved access to professionals for medication needs
- ✓ local knowledge about which paediatricians are recommended for treatment of ADHD

“[The] Diagnosis process - should be made easier. Access to professionals for medication needs to improve.”
(Survey respondent)



“The ADHD diagnosis journey is confusing at best. There isn’t a lot of information which is readily available, and each doctor/psychiatrist/psychologist/counsellor etc seems to have a slightly different approach. I think part of the problem is that the disorder is poorly understood by the general public, so the journey to diagnosis is more often stumbled upon than purposefully sought. And even once someone realises they’re potentially on the path to an ADHD diagnosis, most of the information they get comes from others’ experiences, as opposed to professional advice.” - (Survey respondent)



Increased awareness/resources:

- ✓ ADHD coaching for tweens/kids
- ✓ parenting support/information about children/young people with ADHD and their differing needs
- ✓ support for children with a suspected disability
- ✓ professional development for teachers & educators on ADHD
- ✓ information on accessing free ACT-equivalent programs such as Pathways to Preschool Program (NSW)

“More support and information about parenting a child with ADHD and how each child has different needs and support on their individual type of ADHD.” - (Survey respondent)



“More initiatives like [NSW] Pathways to Preschool (run by Treehouse) and support for undiagnosed children with disability. I have found the experience of parenting a neurodivergent child extremely isolating and the support I did manage to find has been invaluable. Prior to accessing NDIS EI [early intervention], the free programs like pathways to preschool were so helpful and it was not so easy or apparent how to access the equivalent in the ACT.” - (Survey respondent)



Family/parenting support:

- ✓ to help set up routines and trouble-shoot
- ✓ home care in afternoons with larger families
- ✓ a list of service providers that can assist with in-home support, e.g., babysitting, tutoring, cleaning; assistance with social outings
- ✓ respite for carers through organised activities for children, e.g., camps

"Giving caregivers a break with camps for the kids or something. We always get the worst of our kids time and finding any kind of relief is incredibly difficult."

- (Survey respondent)

”

"I struggle with social outings and what other things. What children need is the family to be supported not just them."

- (Survey respondent)



► Support needs in the education system

The following charts highlight the emphatic support received for suggested improvements in relation to support needs in the education system, such as who to talk to in relation to a child's ADHD needs, and ADHD education for educators/teachers.

Approximately 80% of respondents agreed that clear information about who to talk to in relation to a child's ADHD needs would be 'helpful' or 'extremely helpful' (4 or 5). Even more respondents (87%) agreed that education for educators/teachers in understanding ADHD and how to support children and families with ADHD would be 'helpful' or 'extremely helpful' (4 or 5).

Chart 10: Would clear information about who to talk to about your child's ADHD needs be helpful? (101 responses)

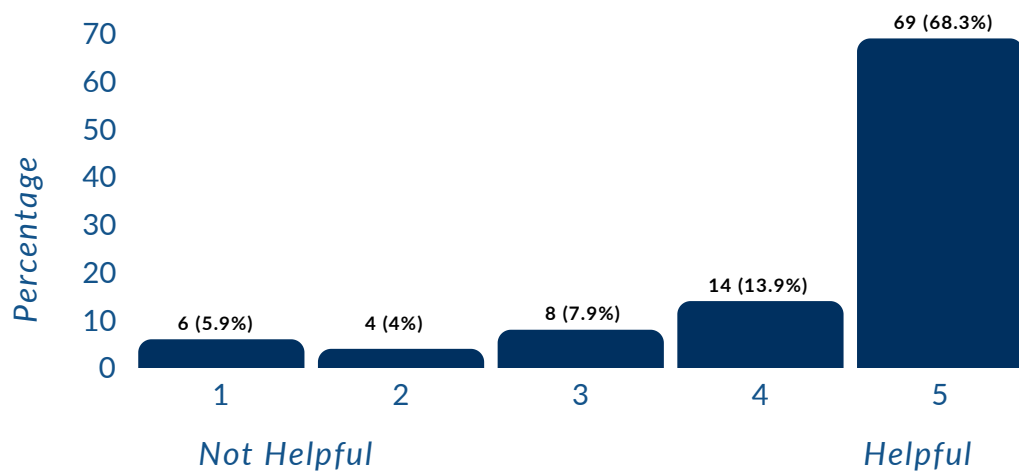
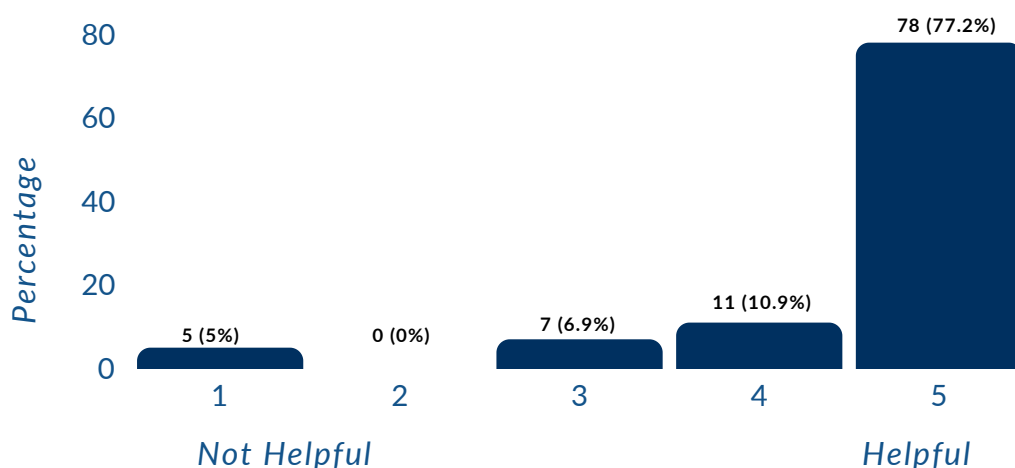


Chart 11: Would education for educators/teachers in understanding ADHD and how to support children and families with ADHD be helpful? (101 responses)



Respondents also provided numerous suggestions to address support needs in the education system. These can be grouped into three key themes, with the first in particular garnering significant attention among respondents.

- ✓ Increased understanding of ADHD among schools/teachers.
- ✓ Support for students to become more self-aware and to manage their ADHD, e.g. executive functioning, social skills, behaviour, personal space.
- ✓ Behavioural support for students to stay at school.

Increased understanding of ADHD within schools:

- ✓ consistent and regular professional learning and training for teachers/educators on how to meet varying student needs
- ✓ increased awareness of how ADHD may present differently in girls
- ✓ supportive teachers who engage entire class in 'active learning'
- ✓ awareness that individual supports and strategies should be used, rather than blanket strategies for ADHD
- ✓ awareness that children may have ADHD even though they may not display disruptive behaviour
- ✓ increased awareness on the impact of ADHD on families
- ✓ special needs teachers required to undergo special training to ensure solid understanding of the complexity of the issue

"Having teachers understand ways to navigate multiple diagnosis, plus ADHD, would be amazing for my child." - (Survey respondent)

"Education for educators, teachers and admin is vital for continued support." - (Survey respondent)

"Support in school is so lacking, having support and education for teachers would make huge difference." (Survey respondent)

"The public schooling system consistently misses diagnoses of children with ADHD when they do not display disruptive behaviours as they are focussing on the children who are disruptive or creating unsafe environments." (Survey respondent)

Supporting students to manage ADHD:

- ✓ provisions made and adequate support provided to students
- ✓ help for other students to understand ADHD and not bully

“Our school [name removed] primary does quite well in our opinion with supporting our children to stay in mainstream class and [implementation] of IPL. I know this is not the same for other primary schools and I hear high school most definitely is a challenge.”
(Survey respondent)

”

“Our whole education system needs to revamp and provide support for these kids. ADHD gets no additional funding so children with severe combined ADHD fall through the cracks or get lumped in support units where their needs are not met.”
(Survey respondent)

School supports to manage student behaviours:

- ✓ support to ensure students can stay at school and be supported to manage their behaviour

“School support, so they can stay at school and not be sent home all the time.” (Survey respondent)

”

“Schools needs to stop sending the kids home, either by suspension or bullying parents into shorter days etc.” (Survey respondent)

“Understanding how hard it is to get a child to attend school with ADHD.”
(Survey respondent)

4. Key themes to inform next steps

The survey findings provide clear outcomes in terms of suggested programmatic responses, including that:

- ✓ For **children**, there is strong support for programs with practical strategies, as well as recognition of additional needs in the education system, such as clear information about available staff to talk to in relation to a child's ADHD needs, and ADHD education for all educators/teachers.
- ✓ For **parents and other family members**, there is significant support for improvements such as information sessions and education for the whole family, as well as increased access to additional resources including health sector support, awareness/information, and family/home support.

Overall, the survey findings illustrate the clear supports needed by families of children with ADHD in the ACT. These include:

- ✓ A more consistent and coordinated approach to diagnosis, with a clear pathway that helps each family understand their journey to diagnosis and supports, both medical and non-medical.
- ✓ A centralised location for reliable information and resources that can be easily accessed and shared among individuals and their supports. This is critical to ensure that people obtain reliable, accurate and comprehensive information about ADHD, and where they can find support. Support from peers and social media were common forms of support in the Village survey, but ensuring reliability and accuracy of this information is vital.
- ✓ Face to face care and support that considers the whole family, that takes into consideration the intergenerational impacts of ADHD, and the high prevalence of co-existing conditions (diagnosed or otherwise).

Approximately half (51%) of survey respondents indicated they would be interested in being involved in the next stage of translating the feedback into action. The Action Group, with their membership representing diverse entities, are well positioned to work with the ADHD community to design responses to address the needs families of children with ADHD in the ACT. This willingness to be involved in co-creating and designing change will help ensure that practical information, resources, and services to support families meets their needs and helps to improve their lived experiences of ADHD within the ACT context.

Appendix One: Partners



Yerrabi Yurwang Child and Family Aboriginal Corporation was established in 2019 due to the high unmet health and wellbeing needs of the local Aboriginal Community residing in Canberra's Northwestern Ngunnawal region.⁸ Yerrabi Yurwang means to walk strong and was bestowed upon the organisation by esteemed and respected Ngunnawal Elder, Auntie Agnes Shea OAM, who is also a Founding Board Member of Yerrabi and the organisation's Inaugural Patron.⁹

Yerrabi Yurwang operates in the Northern region of Canberra, part of the traditional lands of the Ngunnawal People.

Yerrabi Yurwang is an Aboriginal Community Controlled Service, which means it is owned and operated by Aboriginal People, for Aboriginal People, and as such, it is committed to the principle of self-determination, whereby the organisation seeks to engage and empower Aboriginal People and their families who utilise Yerrabi Yurwang's services.¹⁰

Yerrabi Yurwang's purpose is to facilitate the empowerment of children, families and community, building on their resilience to improve their health and wellbeing. It is intended that Yerrabi Yurwang's vision is achieved through guiding principles that remain cognisant of the needs, health, wellbeing, development, and aspirations of Aboriginal children and their families.¹¹

Yerrabi Yurwang delivers the **Connected Beginnings Program** in partnership with Village Staff from Yerrabi Yurwang are also involved in Village's activities through membership in the Leadership Group and other Village Working Groups and initiatives. Yerrabi Yurwang highlighted the need for further investigation into the experience and impact of ADHD on Aboriginal and/or Torres Strait Islander children and families. This led to the implementation of the ADHD Action Group which has brought together ACT government and non-government representatives who have agreed to identify opportunities for services and organisations to provide further support to families of children with ADHD, with a particular focus on the local Aboriginal Community.

⁸ Retrieved from: <https://yerrabi.org.au/index.php/about-us-new/> (accessed 12 December, 2023).

⁹ Ibid.

¹⁰ Ibid.

¹¹ Ibid

A Village for Every Child

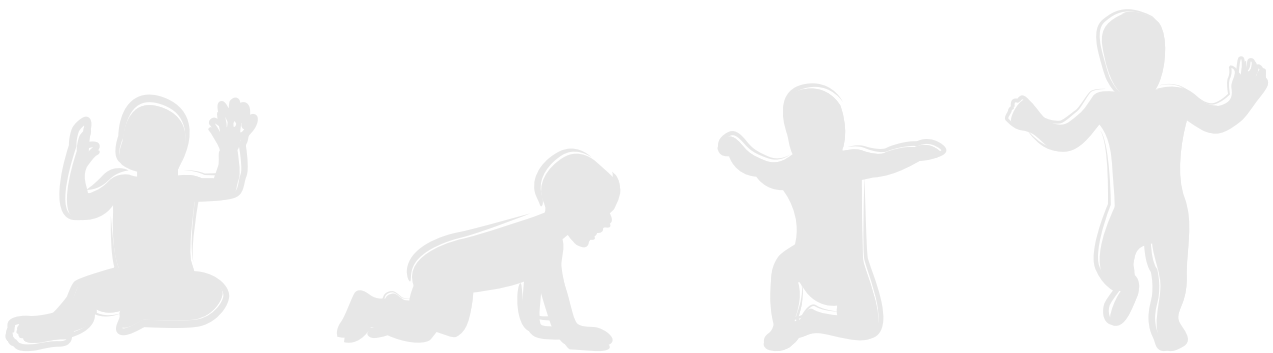


A Village for Every Child (Village) is an initiative that aims to improve systems across Belconnen ACT, so that children are physically healthy, socially, and emotionally strong and ready to engage in learning and life; and all parents are supported, empowered, and equipped. Its focus is on pre-birth to five years of age. Village uses a place-based collective impact framework that operates across the system, working with those in the system to bring about systemic change.

Village brings together a range of stakeholders including families, community members, child and family support organisations, education providers, and government agencies to improve:

- ✓ Awareness about early years development
- ✓ Connection between families and early years services
- ✓ Transitions between early childhood education, preschools, and schools

The role of Village is to connect these parts of the system and facilitate actions that respond to the community needs, and to deliver on the ACT and Commonwealth Governments' strategies that relate to supporting children to thrive. Its role in the ADHD Action Group is to provide coordination, secretariat, and project support.



The ADHD Action Group

The Action Group was formed in response to a need identified in the Village Leadership Group by a member from Yerrabi Yurwang. Concerns were raised about the impacts of ADHD on Aboriginal children, their families and their life outcomes, and a request was made to Village Leadership Group members to bring together experts from across government and non-government to investigate these further.

The Action Group's objective is *"to identify opportunities for services and organisations to come together to provide further support to families of children with ADHD."*¹²

The Action Group is comprised of members representing the following agencies and organisations:

- ✓ Yerrabi Yurwang Child and Family Aboriginal Corporation
- ✓ ACT Government Directorates of Health, Education, Community Services and Canberra Health Services
- ✓ A Good Start in Life – University of Canberra
- ✓ Capital Region Community Services
- ✓ Child Development Service
- ✓ Child and Family Centres
- ✓ EACH
- ✓ ACT Playgroups
- ✓ UnitingCare Kippax
- ✓ A Village for Every Child



¹² Retrieved from: <https://belconnenvillage.com.au/adhd-action-group/>

Appendix Two: Context

ACT Government's Inclusive Education Strategy

In December 2023 the ACT Government released *Inclusive Education: A Disability Inclusion Strategy for ACT Public Schools 2024-2034*¹³ (the Strategy). To develop the Strategy the Education Directorate commissioned an independently facilitated Community Conversation¹⁴ to hear how students with disability and their families experience the ACT public education system. Through the Community Conversation, the Education Directorate heard that neurodiverse children and young people in ACT public schools want their needs to be better recognised and understood.

The Education Directorate also undertook a review of Australian state and territory approaches to disability education and considered research evidence related to inclusive education and specialist settings. The Community Conversation, evidence review, and lessons learned from past engagements helped to inform the Strategy. The Strategy and First Action Plan¹⁵ provide a vision and actions to strengthen inclusive practices in ACT public schools to deliver tangible outcomes for students with disability.

Resourcing has been provided to deliver professional learning resources in key areas such as universal design for learning, managing complex behaviours, and understanding neurodiversity. Work to develop and prepare for a new adjustment-based resourcing model for students with disability is also underway.

Senate Inquiry:

Assessment and support services for people with ADHD

The increased attention and acknowledgement of the experience of these families has been more recently recognised at the national level through the Senate Inquiry into the assessment and support services for people with ADHD.

¹³ Inclusive Education: A Disability Inclusion Strategy for ACT Public Schools 2024-2034
https://www.education.act.gov.au/__data/assets/pdf_file/0005/2338430/Inclusive-Education-Strategy.PDF

¹⁴ A Community Conversation - Summary Report
https://www.education.act.gov.au/__data/assets/pdf_file/0003/2098515/A-Community-Conversation-Summary-Report.pdf

¹⁵ First Action Plan 2024-2026
https://www.education.act.gov.au/__data/assets/pdf_file/0003/2338428/First-action-plan.PDF

On 28 March 2023, the Senate referred an inquiry into the barriers to consistent, timely and best practice assessment of ADHD and support services for people with ADHD to the Senate Community Affairs References Committee. The report was released in early November 2023,¹⁶ drawing on 700 submissions and the evidence of 79 witnesses attending three days of public hearings across Australia.

Throughout the inquiry people with lived experience of ADHD shared the complex challenges they have encountered resulting from government systems failing them. Due to the impacts felt across the education, healthcare, employment, and justice systems, and as a result of stigma of neurodiversity and the expectations of neuronormativity, individuals reported challenges with personal relationships, their mental health, finances and self-esteem.¹⁷

The committee also found that barriers to people with ADHD accessing assessment, diagnosis and support services include the following:

- ✓ Lack of services—limited availability and long wait times for healthcare professionals to diagnose and provide medication and other supports to people with ADHD, lack of services in the public health system, especially for adults with ADHD and insufficient services in rural, regional, and remote areas.
- ✓ High costs of services—including insufficient coverage under Medicare, the Pharmaceutical Benefits Scheme (PBS) and the National Disability Insurance Scheme (NDIS).
- ✓ Poor consumer experiences—caused by lack of reliable information about ADHD, overly bureaucratic processes, fragmented care, inconsistent prescribing regulations, and stigma and variable quality of healthcare associated with ADHD, as well as use of stimulants.
- ✓ Lack of supports in schools, out-of-home care, and correctional facilities.
- ✓ Specific challenges for key groups including girls, women, and gender-diverse people, First Nations peoples and people from culturally and linguistically diverse backgrounds.

Overwhelmingly, people with ADHD want more accessible support to help them thrive and reach their best potential—in their relationships, in their studies and in their work. The committee made 15 recommendations which include addressing the stigma, costs, and barriers to support experienced by people with ADHD.

¹⁶ Assessment and support services for people with ADHD - Parliament of Australia
https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/ADHD/Report

¹⁷ Ibid

Appendix Three: Survey

Survey to understand the needs of families affected by ADHD

This survey has been designed to understand the needs of families that have a child with undiagnosed or diagnosed ADHD and how to support them more effectively. Collecting this information will help us understand where changes can be made at the service level to help improve the experience of families on the ADHD journey. Thank you for taking the time to complete the questions below.

1. What is the age/s of the person/s in your family with suspected or diagnosed ADHD? (can select multiple options)	<ul style="list-style-type: none"> • 0-4 years old • 5-7 years old • 8-16 years old
2. What is your cultural identity?	<ul style="list-style-type: none"> • Australian • Aboriginal • Torres Strait Islander • Aboriginal and Torres Strait Islander • European • Chinese • Indian • Nepalese • Vietnamese • Other
3. Does your family member have a diagnosis or are they in the process of getting one?	<ul style="list-style-type: none"> • Have a diagnosis • In the process of getting a diagnosis • Not diagnosed
4. If you have a diagnosis, what is the level of severity? If unsure, find out more here.	<ul style="list-style-type: none"> • Mild • Moderate • Severe
5. If you have more than one family member please write the age and diagnosis status of additional family members.	
6. Does the family member have other suspected or diagnosed conditions? If so, please list for any relevant family members.	
7. How old was/were the family members when diagnosed?	
8. We have heard that families with experience of ADHD need improvements to the ADHD support system. Below are examples of potential improvements to the system. For each option, please rate on a scale of 1 -5 (1- not helpful, 5- extremely helpful) how helpful this would be/would have been during your ADHD journey?	

Support needs for parents and other family members	a. Would information sessions about understanding ADHD, services & supports, referral pathways and/or access to professionals be helpful?
	b. Would education for the whole family, focusing on specific needs of families/children with undiagnosed or diagnosed ADHD be helpful?
	c. Would social/ support groups be helpful?
	d. Other comments / ideas
Support needs for children	a. Would programs for children that provides them with strategies to learn how to self-manage feelings and behaviours be helpful?
	b. Would a social/support group be useful?
	c. Other comments / ideas
Support needs in the Education system	a. Would clear information about who to talk to about your child's ADHD needs be useful?
	b. Would education for educators/teachers in understanding ADHD and how to support children and families with ADHD be helpful?
	c. Other comments / ideas
Optional text questions	1. What has been the most challenging part of living with ADHD in your family?
	2. What helped during this time?
	3. If you have received a diagnosis or are on the journey to receive a diagnosis, what have been the challenges?
	4. What helped during this journey?
	5. Would you be interested in being involved in the next stage of translating the feedback into action? If yes, please provide your contact details (email or phone)

Appendix Four: Key quotes from survey respondents

Support to find a best-fit school

Early childhood centres and educators are desperately in need of education around neurodivergence and behavioural challenges stemming from dysregulated kids. We were forced out of two different settings, causing much trauma. The ACT education system should also provide funding and support for children with an ADHD diagnosis that are not diagnosed with other types of neurodivergence but which might receive such a diagnosis in the future. We are looking at our child starting school with only a provisional ADHD diagnosis and there will be no extra support despite being unable to cope with a mainstream setting. One thing that has helped us previously was the ACT Gov's three year old initiative, which placed us in a truly wonderful daycare (after a terrible, discriminatory experience elsewhere). That was hugely helpful. However we needed similar assistance for identifying schools/preschools which would be a good fit and it felt that after the assistance with the three year old initiative there was not the same sort of support in identifying schools. We have had to go around and interview schools (the ones that would actually let us do a visit) and whilst we understand the rhetoric that all ACT schools need to accommodate we have no idea if our choice will actually lead to a good/positive schooling experience or if our child will find it traumatising.

Holistic support from schools

All teachers and school staff that interact with children in a school setting need basic training in ADHD and other neurodivergent conditions. This would raise awareness and understand how children differ from their peers. This should be done within schools. Teachers and schools should be open to working with an individual child's external OTs, speech therapists and learning coaches. Our children need a team approach to get the best results. Our public schools need to be better at this.



Challenges of life with ADHD

Intensity of life, consumption of time taken to "prove" need and still not get required "early interventions" is continually frustrating.

Being 'punished' for behaviours that inherently help them learn (ie movement seeking) and not being offered strategies to support "behaviour".

From top level of school - not acknowledging that ADHD requires ILP and that additional modifications to learning are required to ensure child can engage and succeed in learning and social outcomes at school.

It's exhausting as my child is less independent than he could be. Needs prompting for everything. Screen addiction is an issue for him and another source of conflict/stress and guilt. There is always conflict about chaos and 'getting it done'. My son has internalised that he's 'deficient' and is always apologising (low self esteem). I feel terribly guilty about this. We don't feel we are doing enough to help him, desire his diagnosis; we don't really know enough about how we could helpfully intervene.

Dealing with 3 kids all with different levels of ADHD. Having a severe ADHD diagnosis is hard compared to the moderate inattentive too. Walking on egg shells at times as not to set off a meltdown. Lack of parental support or respite. No-one to leave our kids with. They talk about ADHD burnout what ADHD carer burnout?

Feeling impossible to get medical support and appropriate assistance as it's not NDIS funded and has significant out of pocket costs too.

The fact that they just can't do things, even the most basic of things on days, and then some days they do everything. from one extreme to the other. Then some days are just in bed for days.

It's very difficult to pinpoint one, since the challenges can be so varied. But to name a few; excessive mood swings, extreme disorganisation and mess, hyperactivity which affects both good and bad moods for which the end result is the same: an endless stream of information and sound, a lot of which doesn't really have any use. Sleep issues (many interrupted nights for the first 6-7 years), over-sensitivity to the actions of others which leads to friendship issues and problems with authority figures such as sports coaches.

All of us having it.

My son is showing signs of ADHD and I am finding it hard to support his needs as there is not enough information and support for ADHD in the ACT.

Our public school has not met its obligations to provide required supports for my children to access their learning on the same basis as their peers. The education directorate has not ensured that its schools meet their obligations to their students with disabilities, and has not ensured that school leaders and teachers have the required training, experience, resources and accountability to do so.

School refusal, severe anxiety linked to failure as a learner and as an individual. Having so many specialists say that my daughter exhibits ADHD behaviours but she [could] do well in primary school that now age is older and failing to thrive she is unable to be diagnosed and get the help she needs. Schools having no idea how to support a student in crisis.

Total lack of paediatrician with open books within the ACT.

There does not seem to be a common path to diagnosis, or if there is every professional I've spoken to has a different idea of requirements, who can formalise diagnosis.

Waiting for paediatrician and psychology assessments, cost of paediatrician and psychology assessments, difficulty getting in to act public school psychologist, lack of allied health at the private school.

The cost is huge. Every psychiatrist appointment is about \$400. I am breastfeeding so I had to convince my psychiatrist to prescribe medication to me. The waitlist for a paediatrician appointment is 12 months long and most Canberra paediatricians have their books closed to new patients. In addition to that, the first appointment is going to be \$650. My daughter has so many sensory issues and I am on the waitlist for an occupational therapist, so the sensory issues have been so overwhelming.

Too expensive and never been able to find a bulked billed way to do this, had to go without diagnosis for ASD for daughter and psychologist support as we cannot afford it.

Supporting a young adult transition[ing] from school and a paediatrician, to working life and other medical professionals.

Cost and access. Youngest son 5 was diagnosed by a Canberra psychologist over 3 sessions and that was close to \$5000. Then the other 2 used a Sydney based team that travel to Canberra and were only \$1100 for a more detailed report. Trying to get into a paediatrician. My daughter had testing this time last year. We see our son's paed [in] March next year.

Waiting times and then having to go to Sydney for a diagnosis.

Support for families living with ADHD

Anything would help.

When you make friends with other families whose children have ADHD. They understand.

Having someone to talk through who has been through the process would have been helpful. I know lots of people now, but when my oldest was first diagnosed in year 1, I didn't know anyone. Friends and family liked to tell me I was making the wrong decision, however I know I made the right one as my son could actually begin learning once he was medicated.

Intensive occupational therapy (\$193.99 for a 45minute session once a fortnight) which we pay out of pocket for due to not being eligible for NDIS funding. Without this therapy, our family would be in a world of hurt.

Additional medication for myself as a parent to support my ability to parent longer periods of time as well as radical acceptance - our family will never look/sound like average households and that's ok.

We have learnt to let some things slide, our aim is to be on time for school but if it doesn't work we don't stress. We offer choice to our youngest to allow for her defiance to be minimal.

Choosing timing and location to socialise somewhere tolerant of children not staying seated / food choices accepted eg snacks not meals. Allowing kids to use iPad to regulate.

Content shared by ADHD social media influencers. The content shared isn't medical advice but it does help to understand symptoms, know it's not just your child, and show we aren't alone in the struggle.

Being able to get some OT and psychology through UC's Health Hub.

Reading information, my husband and I talking to each other, taking a break from the regular day to day routine (going away for the weekend). Once our daughter started medication (Ritalin) and we found a good dosage life is much easier.

There are too many things to list. But some standouts for us have been an amazing ADHD coach, and a group of public school teachers who we are incredibly fortunate to have. Medication has been an absolute saviour of our sanity, and melatonin has helped a lot with sleep issues.



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