



18 September 2023

AUSTRALIAN SENATE

Senate Community Affairs References Committee

Via e-Mail: Community.Affairs.Sen@aph.gov.au

Dear Senate Community Affairs References Committee,

RE: ADHD SUPPORT SERVICES ENQUIRY

SCOPE

The Senate Community Affairs References Committee (committee) is examining evidence on how access to assessment and support services for people with ADHD could be improved.

To date, consistent evidence has been received that multiple pathways exist for individuals to access assessment and treatment. Further, these pathways can be convoluted and difficult to understand and navigate.

As part of its inquiry, the committee has been tasked with examining ways of improving existing ADHD assessment and support pathways.

The committee therefore seeks your organisation's expert advice on what it considers to be the best practice approach for all stages of the ADHD assessment and treatment process— from initial assessment and diagnosis, through to medication (as required) and other treatment, as well as ongoing support and treatment plans.

The committee would welcome receiving your organisation's response in the best way you see fit. The committee is aware that the process has been presented in other forums as a flow diagram, in support of accompanying text.[1] You may choose to respond in a similar way.

The committee suggests that any proposed pathways should take a person-centred approach, with your response indicating your views on which body or organisation should be responsible for providing the service or support, and where government support should be provided (e.g. Medicare, PBS).

The committee would also appreciate any expert views your organisation may have into the separate pathway needs of children who are suspected of having ADHD.

A response by close of business, Friday 28 September 2023 would be appreciated. Please email your response to Community.Affairs.Sen@aph.gov.au

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The ADHD Foundation thanks the Senate Community Affairs References Committee (committee) for the enormous amount of work that is being completed to examine the huge amount of evidence, lived experience and expert knowledge in order to assessment and support services for people with ADHD.

Thank you for providing the opportunity for our organisation to provide some additional information on what we consider to be the best practice approach for all stages of the ADHD assessment and treatment process—from initial assessment and diagnosis, through to medication (as required) and other treatment, as well as ongoing support and treatment plans. With our response we have create a presentation that may be helpful. The ADHD Foundation has sourced information internationally where other countries are also developing better understanding and best practice for those with ADHD. We have created our presentation based on this and our own National ADHD clients who contact us through the National ADHD Helpline.

In this response we haven't addressed any views on the pathway needs for children apart from the fact that we understand the immense financial pressure that families face to obtain the necessary support for a child with ADHD. Particularly when the child is not eligible for support through NDIS or another funding.

BACKGROUND

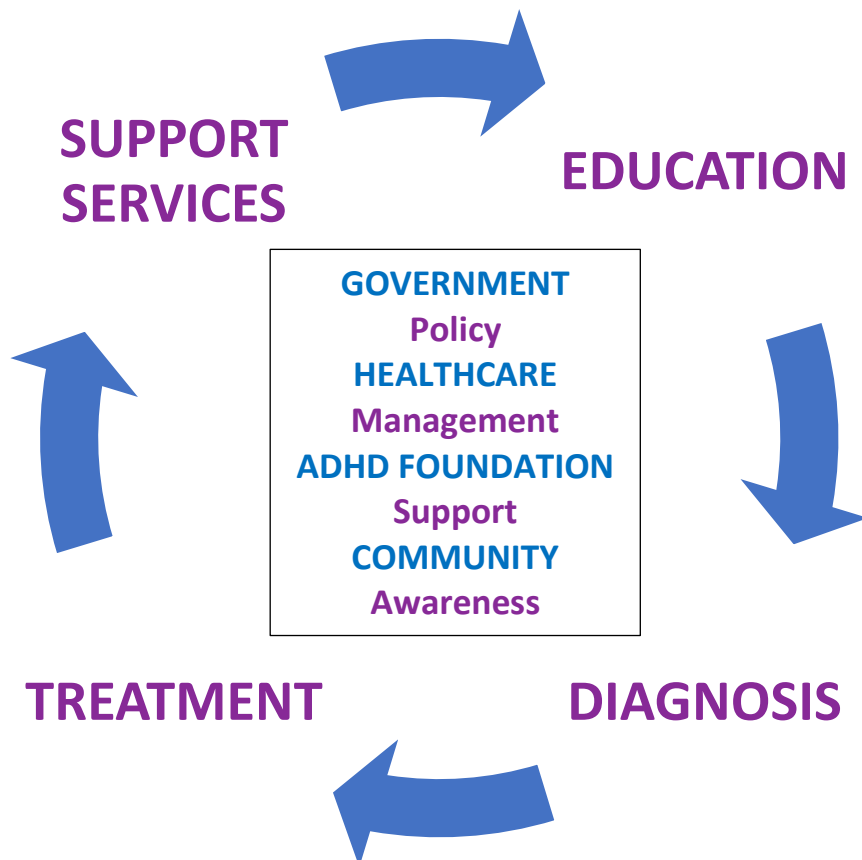
The ADHD Foundation is registered with the ACNC as a for purpose not for profit charity. The organisation was established in 2017 and via its National Help Line currently manages close to 10,000 thousand enquiries per year from people with ADHD or seeking support towards assessment for ADHD and other related conditions and those who support them. Many of the calls relate to requests for diagnosis and treatment options. A large percentage of enquiries come from those seeking guidance after having been exploited, other callers are on the verge of suicide. The ADHD Foundation is therefore highly qualified to provide insights into the community experience regarding the treatment of those with ADHD and current healthcare system inadequacies and required improvements.

The ADHD Foundation recommend a four-tier action plan designed to address current issues driven by Government, Public and Private Healthcare, the ADHD Foundation, and the Community.

The following information contained in this document provides an overall recommendation distilled from our submission to the Senate enquiry and highlights our over all approach for change.

Our presentation provided with this response focuses more on a suggested pathway and alignment with services and support for a patient who is at the discovery stage and unsure whether ADHD may be a driving factor in their lives. The ADHD Foundation finds that 90% of clients contacting the helping are confused by the amount if information provided to them from friends, social media and sites where mis information lies. Getting to the diagnosis is sometimes the most stressful and financial inhibitor for those seeking help.

If ADHD is a condition that a child is born with then ADHD is a lifelong condition and therefore at every stage of a life journey ADHD has an impact on the well being of that person. To encompass all stages of this ADHD journey, then government needs to review all mental health and public policies to include ADHD as a primary mental health condition. This change is by no means easy but over all the ADHD Foundation has highlighted these areas in the diagram below.





1) EDUCATION

Misinformation and lack of knowledge about ADHD is negatively impacting our community. Education is the first step to addressing the current impasse and is essential to driving holistic and effective change. As such the ADHD Foundation believes investment must be made across three target groups:

a) Primary & Secondary Schools

Primary and Secondary school's must deliver an annual training programme to their educators around ADHD and general neurodiversity including observational and paper based screening. In addition, educator training around ADHD and neurodiverse student management must be incorporated into annual training programmes.

As an extension to this, programmes designed for children on neurodiversity should be developed designed to destigmatise the condition and assist in building empathy amongst the student cohort.

b) Workplaces

Employers must deliver an annual training programme to their staff around ADHD and general neurodiversity and how to work productively and accommodate the needs of the neurodiverse. Such programmes would also be designed to destigmatise the condition and assist in building empathy amongst staff.

c) Healthcare Professionals

ADHD Training should become a core subject for all healthcare professionals. This includes Psychiatrists, Psychologists, General Practitioners, Nurses and Allied Health professionals. ADHD diagnosis, treatment and behaviour management should become mandatory healthcare course content.

d) Community

A public awareness programme covering ADHD and neurodiversity should be introduced designed to destigmatise the condition, build empathy and provide awareness on how to manage certain behaviours sensitively.

The ADHD Foundation already provide public and private awareness education programmes and supply valuable information and resources via their website and National Help Line.

2) DIAGNOSIS

Accurate diagnosis is essential to ensure optimal quality of life and community outcomes. Currently only specialist trained psychologists and psychiatrists can diagnose ADHD. There are currently insufficient medical professionals in the Australian healthcare system to meet the growing demand.

Parents of young children and primary and secondary schools are the ideal audience to alert medical professionals about suspected neurodiversity. Research can be accessed via the ADHD Foundation website and National Help Line but ultimately qualified and ADHD trained mental health professionals can only diagnose ADHD and recommend further action.

Public Health

- a) The public health system must firstly recognise ADHD as a primary condition and recognised as part of the Mental Health Public Policy Framework.

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- b) ADHD patients must then be given access to diagnosis options within the public health system.
- c) The public health system must ensure its public psychologists, psychiatrists and general practitioners are trained in ADHD from an awareness, diagnosis, treatment and behavioural management perspective. All patient facing staff must also be trained in ADHD behavioural management.
- d) General Practitioners should be permitted to diagnose ADHD and provide Psychiatric referrals.

Private Health

- a) The private psychology and psychiatry health sector is currently diagnosing and treating ADHD but there are insufficient trained professionals to meet the demand. Often this leads to exploitation. As such, government pricing regulation should be introduced to prevent exploitation, allowing for more affordable diagnosis and referrals to psychiatrists.
- b) General Practitioners should be permitted to diagnose ADHD and provide Psychiatric referrals.

Children, Adolescents & Adults

- a) Diagnosis programmes need to be tailored for Children and Adolescents and Adults.

The ADHD Foundation already provide public access to ADHD assessment tools including valuable information and resources via their website and National Help Line. That said only properly trained mental health professionals can confirm an ADHD diagnosis.

3) TREATMENT

The ADHD Foundation recommends applying as the standard, the Australian Evidence Based Guidelines for ADHD Treatment as published by the AADPA.

Initially ADHD trained Psychiatrists are the best qualified to stabilise and medicate patients.

Once the condition is stabilised, the ADHD Foundation recommend ADHD trained GP's take responsibility for the ongoing management of the condition.

- a) NDIS

The ADHD Foundation recommends ADHD treatment be accessible via the NDIS with qualifying assessment criteria reviewed by ADHD specialists.

- b) PBS

ADHD Medications must be included within the PBS and made affordably available to patients.

- c) Children, Adolescents & Adults

- i) Diagnosis and treatment programmes need to be segregated between Children and Adolescents and Adults.
- ii) Once diagnosed children reach adulthood, retesting should occur to ensure any required medications are effective.

The ADHD Foundation already provide private referral networks to mental health practitioners.



4) ADDITIONAL SUPPORT SERVICES

a) ADHD Foundation National Help Line

ADHD Foundation National Help Line is currently processing thousands of enquiries per month. With additional funding it could increase the level of community support and act as a resource to current public healthcare systems. As a front line operator, the ADHD Foundation National; Help Line would take pressure off the public healthcare system managing enquiries and providing referral pathways. The ADHD Foundation is recognised as Australians leading community based ADHD service provider.

b) ADHD Foundation Website

The ADHD Foundation provides public access to ADHD assessment tools including valuable information and resources via their website. Information includes ADHD diagnosis tools, medical research, treatment options, behaviour management advice, articles, case studies, education and international collaborations designed to improve knowledge, quality of life and community outcomes.

CONCLUSION

The ADHD Foundation would like to continue to be part of the solution and officially partner with government where its high value, high impact community services could be expended to accommodate the growing demand for ADHD information, diagnosis, treatment and behavioural management.

The ADHD Foundation are convinced that effective management of ADHD will lead to a decrease in:

- Crime
- Domestic violence
- Family separations
- Absenteeism
- Unemployment
- Homelessness
- Education drop-outs
- Substance Abuse

and an increase in national productivity.

The ADHD Foundation would welcome ongoing dialogue and involvement in both the scoping and execution of an effective strategy designed to improve the lives of those with ADHD, their carers, employers and the wider community.

We thank you for this opportunity to contribute to the development of a solution.

CHILDREN



ADULTS



The ADHD Foundation is a national community focused charity delivering support services across Australia and offers a first point of call solution to finding reliable and Information, referral options, direction on ADHD.

As stated in our submission to the Senate Enquiry we recognise that the future of improved, effective and efficient support for those with ADHD requires an integrated service within the mental health community health service.

The ADHD Foundation continues to grow its services to the ADHD community through being innovative, practical and diligent about how we deliver consistent help. We do this with a small dedicated team of passionate, practical and solution driven volunteers. We operate on a 100% volunteer workforce and with the help of donations from our community.

ABOUT THE ADHD FOUNDATION



ADHD
Foundation

Adult ADHD services present a significant challenge to government and service providers alike. The Senate enquiry, public hearings within the Australian community and professionals and medical colleges have all facilitated an opportunity to redesign and integrate, rather than isolate ADHD services between primary and secondary care.

The presentation outlines a proposed pathway designed to ease the journey for those seeking support for ADHD and aiming to reduce stress, anxiety, and overcharging of services. The ADHD Foundation National Helpline is currently in operation, offering reliable and cost-effective services to those grappling with ADHD.



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**“ADHD IS A LIFELONG CONDITION
NEEDING CONSIDERATION AT
EVERY STAGE OF LIFE”**

The scarcity of consistent and credible ADHD educational materials is another concern. We propose standardizing these materials through the ADHD National Helpline and disseminating them across relevant websites.

The ADHD Foundations role would be to ensure that there is no additional burden on GP time by providing the patient with the support and assistance to complete the self-assessment, prepare for the appointment according to requirements and provide the GP with the availability of appropriate specialist availability by providing access to the ADHD Foundation Referral Availability database

This could provide valuable information to those awaiting appointments or even obviate the need for services for those with minor needs.

Patients who decide against ADHD medication can be redirected to other service points, avoiding unnecessary appointments.

This ensures there is not additional burden on GP's



UNDERSTANDING THE PROBLEM

Globally 5.9% of the population live with ADHD

Despite evidence-based national guidance in the UK, Australia, US, Canada and other countries, ADHD remains under-identified, under-diagnosed and under-treated. The ADHD Foundation estimates the over 1million Australian population have been diagnosed with ADHD.

In Australia, a large number of adults living with ADHD are undiagnosed with high rates being those in regional and rural Australia.

ADHD is a neurodevelopmental condition that results in a spectrum of behavioural such as inattention, memory, disorganization, productivity, impulsivity symptoms including inattention and hyperactivity-impulsivity.

It is a heritable disorder with a lifespan perspective: from childhood to teenage, persisting in adulthood through to old age, with significant psychosocial impairment and a high comorbidity rate.

It is associated with high levels of personal distress, and a substantial economic burden for society if left unidentified and untreated.

ADHD is well studied in children, until recently, much less was known about the disorder in adulthood and this is reflected in the enquiries received on the ADHD Foundation Australia National Helpline.

ONE THIRD OF THOSE LIVING WITH ADHD OFTEN DEVELOP SIGNIFICANT PROBLEMS

It is estimated that one third of adults may progress satisfactorily into their adult years, another third continues to experience some level of problems, while a final third continues to experience and often develops significant problems related to ADHD.

Research also shows that disruption of care during transition between services adversely affects clinical outcome. (Singh. 2009) People living with ADHD could have a reduction in life expectancy by as much as 13 years and risk of suicide is five times higher than those without ADHD.

There are proven links with a wide variety of other health conditions including eating disorders, dyslexia, and inflammatory conditions, as well as over 40 per cent of people living with ADHD being co-morbid with other mental health conditions such as anxiety and depression. There is also a particularly close link with people living with ASD.

Comorbidities are unseen costs to the NHS and often result in urgent care services. Unseen costs are generated elsewhere in society where adults are left undiagnosed and untreated. .

3 Faraone et al., 2006. 4 Singh., 2009.



CURRENT STATE OF AUSTRALIA ADULT ADHD SERVICES

THERE IS NO CONSISTENT APPROACH TO PROVISION WHICH RESULTS IN VARIATIONS IN CARE.

This is what the ADHD Foundation have stated in the media and in our submission to the Senate enquiry into ADHD.

- Demand significantly outstrips capacity in adult ADHD services. While in the past most people with ADHD were diagnosed as children, growing numbers are diagnosed as adults.
- Adult ADHD services offer a diagnosis in secondary care (psychiatrist) with prescribing where necessary requiring a review as per each state legislation. The delivery of adult ADHD services in the regional areas are fragmented and delivered by various providers who have experienced a high turnover in recent years.
- There is no single approach to provision which results in variations in care. The transition from child services is inconsistent, which also has a negative impact on adult care.

The shortfall in capacity means access is severely restricted to secondary care. This results in:

- Long waiting times
- Withdrawing their services (full books, retirement etc)
- Professionals are unwilling to accept referrals , leaving many in primary care without access to support.
- Extreme practice of overcharging by some secondary care and allied health professionals.
- Regulations differ across all states - resulting in huge issues for people moving states.

WHEN SPEAKING TO OUR ADHD COMMUNITY VIA THE ADHD NATIONAL AUSTRALIAN HELPLINE WE HAVE BEEN TOLD THAT:



- The National ADHD Support line needs funding in order to provide efficient systems to individuals to find accurate information in order to start the process to assessment and/or diagnosis
- There is no specific pathway for an individual to obtain direction manage their condition.
- Costs of diagnosis are prohibitive when seeking an assessment and ongoing management of their condition.



- Huge waiting times adds stress, anxiety and depression and affects function ability, work, family and relationships.
- GP are removed from being able to support and manage ADHD along with other condition.
- Psychiatrists mostly registered to prescribe in a certain State and scripts not easily filled outside of State of issue.



REDUCE THE BOTTLENECKS:

- Accepting ADHD as a Primary conditions within the public sector therefore opening a larger cohort of psychiatrists who can diagnose
- Changing cumbersome state-based legislation and regulations causing duplication of services in different states.
- Adults on ADHD medication having to be re-assessed if they move States or their current provider ceases operation resulting in re-diagnosis because there are not central point of reference and storage for patient records.
- Providing ability for ADHD scripts to filled in States other than the state it was issued in thus reducing these bottle necks.
- Engaging the ADHD Foundation National Helpline to provide accurate information to those seeking to understand if more about ADHD and next steps.
- Providing funding to the National ADHD Helpline to allow more support services to those who have mild symptoms and who may or may not require medication.

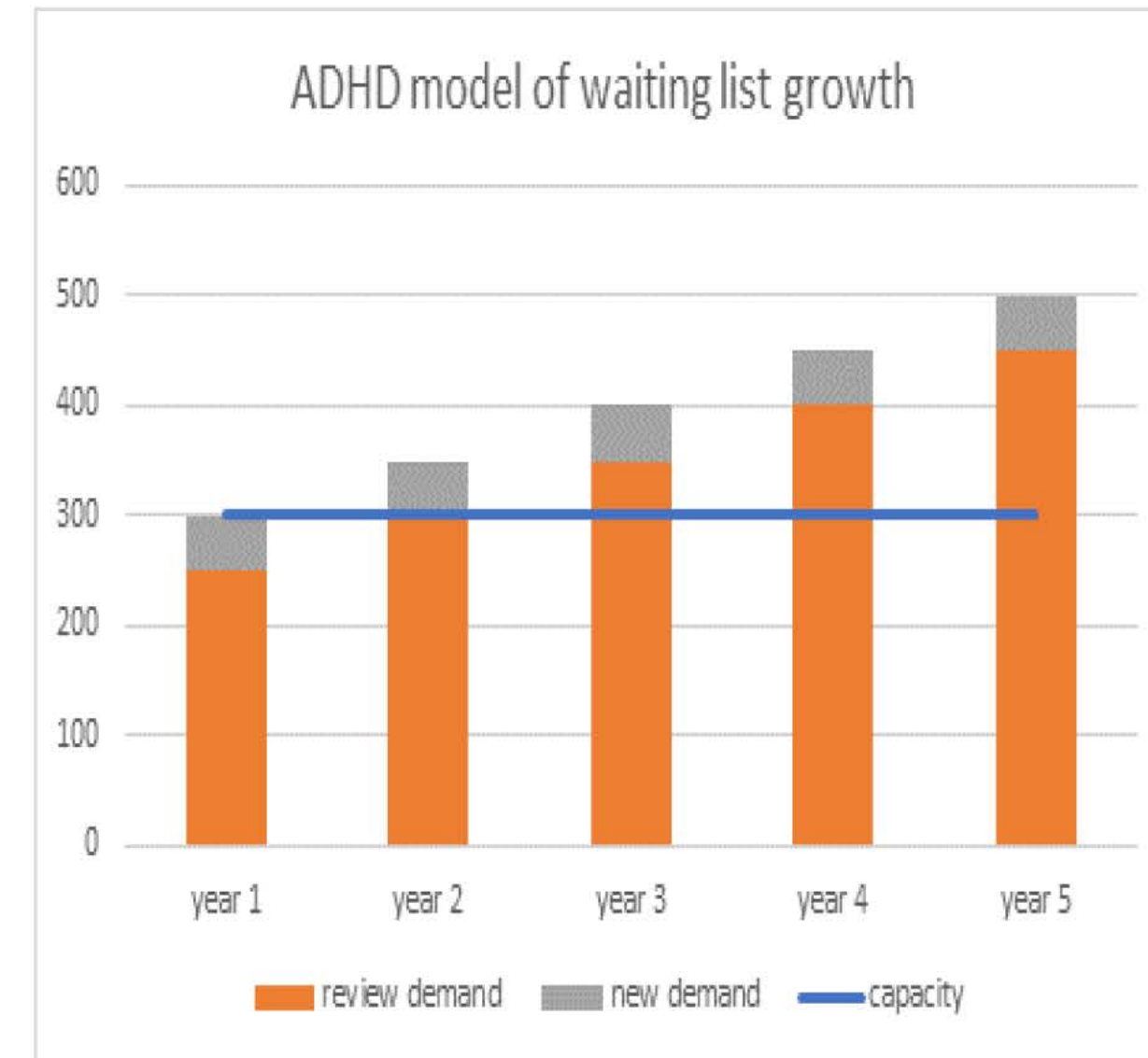
SITUATION WITHOUT CHANGE

Currently the service is typically managed with a referral and waiting list for secondary care (psychiatrist). However, if script renewals remains the responsibility of the secondary care (psychiatrist), instead of the primary care provider (GP) then the renew capacity will continue to grow, thus reducing intake for new patients. he following ways;

- Increasing the number of medical practitioners.
- Increasing ongoing management of patient to primary care provider ie. GP.
- The ability to transfer patients who have stable on medication. Their care is transferred back to their primary care (GP) for ongoing care.

(Primary Care assumes GP): (Secondary Care is Psychiatrist specialist etc.)

WHAT HAPPENS IF NOTHING IS DONE AND WHY WE HAVE REACHED THE CRISIS, WE NOW FIND OURSELVES IN.



Australian ADHD Foundation National Helpline, we have recommended three priorities in our submission. Below is an example of what we see and hear from across Australia.

:

CHANGE

1

FIRST POINT OF CALL: ADHD NATIONAL HELPLINE

- Provide financial support to the ADHD Foundation National Helpline to increase the support and service at the first point of call
- Support the ADHD Foundations data collection centre to inform government of needs

CHANGE

2

GOVERNMENT ACCEPT ADHD AS A PRIMARY AND LIFELONG CONDITION

- Government establish and standardise a national framework, protocol, policy and address ADHD as a primary condition with the public health, mental health, education, justice and other agencies..

CHANGE

3

POLICY CHANGE IN LINE WITH ADHD ACCEPTANCE BY GOVERNMENT

- Review, amend policies, regulations, and legislation to include ADHD as a primary mental health condition in all national and state government agencies. Health, Education etc
- Allocate funding for the high level category who may be financially disadvantaged needing assessment diagnosis and medication.
- Engage with State governments to regulate and standardize and remove cross border restrictions.

CHANGE

4

ADHD EDUCATION AND TRAINING

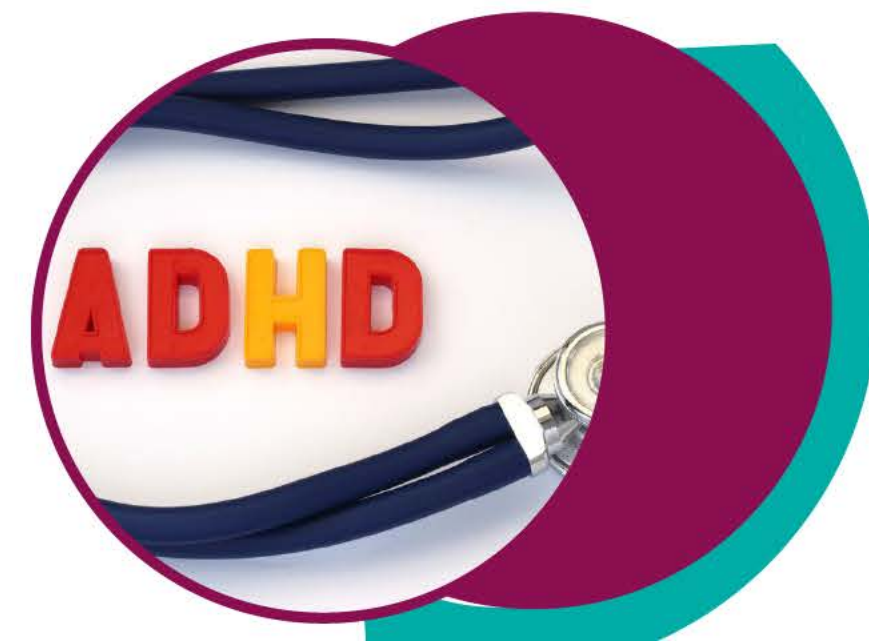
Establish collaboration between government and the Medical Colleges, Universities and other training organisations to ensure that ADHD education and training is accredited and included.

CHANGE

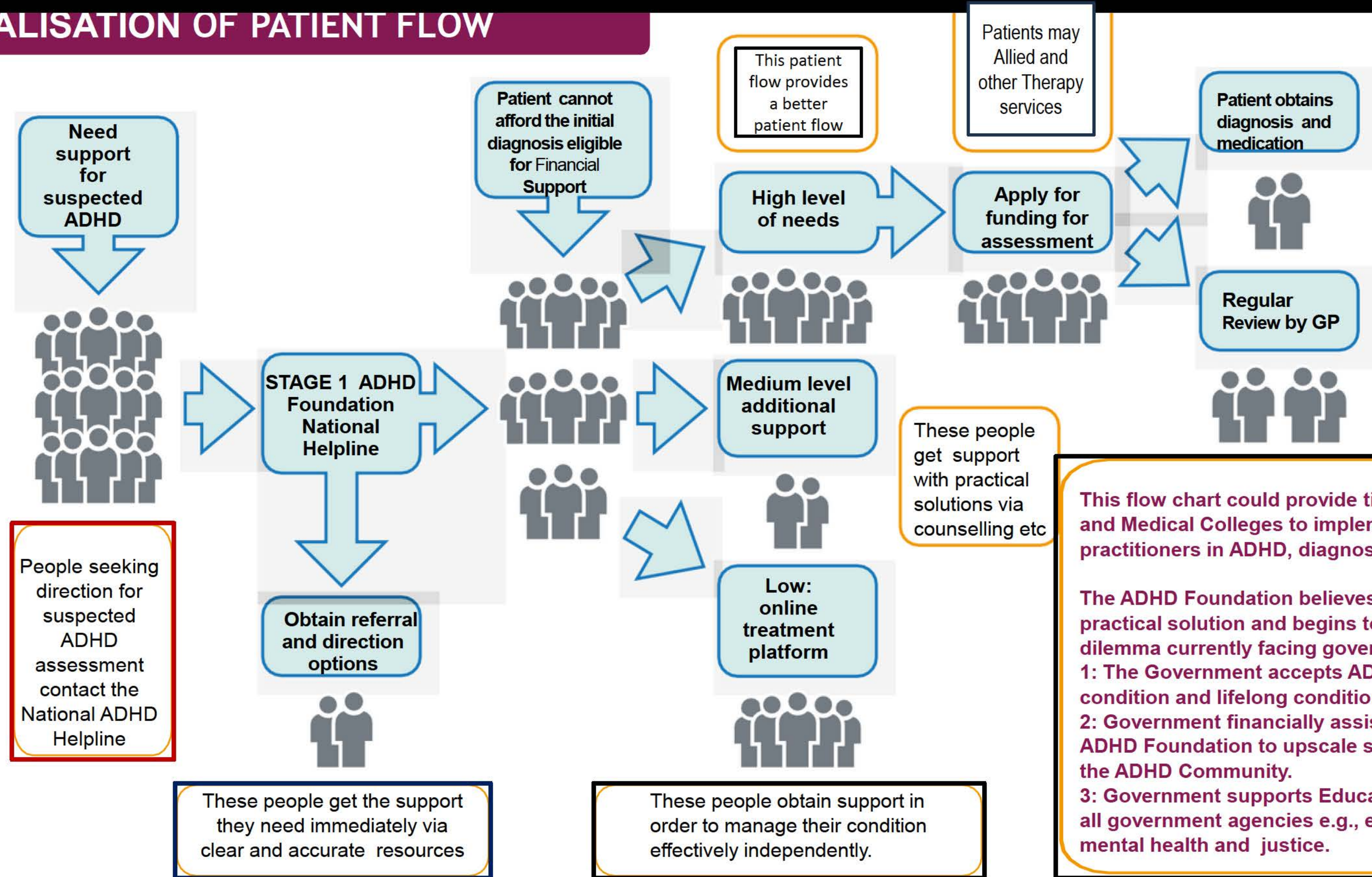
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ANNUAL REVIEWS IN PRIMARY CARE

- Enable annual reviews to take place in primary care, protecting capacity for new referrals in secondary care.
- Not all those with ADHD, either taking or not taking medication, require financial assistance. However, young people in custody, families on social welfare and individuals who are struggling to get their life back on track may require some financial assistance, whether it is the NDIS, bulk billing or Centrelink or another support.



VISUALISATION OF PATIENT FLOW



This flow chart could provide time for Government and Medical Colleges to implement training for practitioners in ADHD, diagnosis and treatment.

The ADHD Foundation believes that this is a practical solution and begins to bring logic to the dilemma currently facing government.

- 1: The Government accepts ADHD as a primary condition and lifelong condition.**
- 2: Government financially assists the National ADHD Foundation to upscale services to support the ADHD Community.**
- 3: Government supports Education and training in all government agencies e.g., education, health, mental health and justice.**

Diagram adapted from www.innovationagency.nhs.uk



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WHY CHANGE?

BECAUSE THE CURRENT SYSTEM IS BROKEN AND NOT EFFECTIVE OR EFFICIENT FOR THE PATIENT, PRACTITIONERS, OR THE GOVERNMENT.

WHOLE SYSTEM AND POPULATION BENEFITS -

IMPROVEMENT TO PATIENT CARE

- Streamlined processes and a patient flow pathway to better health and wellbeing.
- ADHD is considered a primary condition
- Recognition that ADHD is a lifelong condition and not discriminated against in government agencies
- More access to the treatment that they need.
- Realistic cost of assessment, diagnosis and treatment
- Less wait time for assessment and treatment
- Less mis diagnosis as more practitioners are qualified to understand, and treat ADHD
- Ability for reduced costs relating to assessment and diagnosis through Medicare, Centrelink or NDIS etc., for those who meet the criteria
- Less disruption to education
- Less down time for employers, sick leave, more productive workforce.
- Less workplace disruptions, conflicts between employer and employee
- Supporting people back into the employment – providing less depression, anxiety and other debilitating conditions.
- Less doctors' visits, lost employment and income.

GOVERNMENT BENEFIT

- Acceptance of ADHD as a primary condition therefore avoiding necessity for excess expense on government facilities, human resources, duplication of services etc,
- Reduction on costs associated with medications and treatments that do not address the ADHD condition.
- A streamlined and connected health system working to support those with ADHD .
- Reduction of costs associated with a State based system
- Reduction of costs relating to duplicate visits to primary and secondary providers i.e., Medicare rebates
- Reduction in other medication costs that may not be correct
- Less requirement for costs that may be related to management and control related to undiagnosed adults such as justice related offences, illicit drug use,

PRIMARY CARE PROVIDER BENEFIT

- More training for GP's in the understanding, management and ongoing care for patient.
- Less repeat visits to GP to find available secondary care practitioner
- Less time for required to investigate options
- Increase in level of patient needs that include ADHD

SECONDARY CARE BENEFITS

- Collaborative care model between primary and secondary provider.
- Integrated patient record enabling primary care Assessments to be transferred and not duplicated
- Script renewals released to primary care provider protecting capacity for new referrals and maintaining low waiting lists