Prescription of Medication for ADHD

Health and Social Security Scrutiny Panel

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States of Jersey
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États de Jersey
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Chair's Foreword

Many islanders will have heard the term ADHD over the years as most commonly applied to 'little boys who have trouble sitting still and listening to their teacher'. But the condition is far more complex than this. It affects girls as well as boys. It affects adults across the whole lifespan. Global awareness and understanding of this issue has increased massively in recent years and thus it was brought to the attention of my panel.

Attention deficit hyperactivity disorder (ADHD) is defined by the World Health Organization as being characterised by:

> *"a persistent pattern of inattention and/or hyperactivity-impulsivity that has a direct negative impact on academic, occupational, or social functioning, the level of which is outside the limits of normal variation expected for age and level of intellectual functioning."*

We were sent a significant number of submissions from islanders who told us of the lifelong struggles they had experienced. They describe how painful it is to feel as though you are different from others around you, to have difficulty with tasks that are expected to be simple for most, and to feel misunderstood and constantly striving to keep up with the rest of society. We learnt that ADHD impacts islanders from all backgrounds and all levels of education.

It is clear that these hundreds (likely thousands) of islanders have so much to offer and must be supported so that they can fully function and contribute to our island. The current waiting list for adult ADHD assessments stands at well over 700. This is on top of around 300 islanders who are already being treated via the hospital and are experiencing difficulties obtaining the regular prescriptions that they need to function. It is not known how many islanders are resorting to paying for services privately, often at significant cost causing hardship to some. Too many islanders are being let down by our current system.

One key thing that the panel learnt from carrying out this review is that for many with this condition, it is very easily treatable. We heard of the truly life-changing effects of medication for some. We decided to keep the scope of this review narrow and focused on the prescribing of ADHD medication as the key challenge that members of the public were raising with us. The panel found that there are several barriers to accessing appropriate treatment for ADHD including:

- Global shortages of ADHD medication
- A very long waiting list for a hospital assessment
- Only one hospital consultant with an already large caseload
- High costs for a private assessment including ongoing medication costs
- No shared care agreement with GPs so they are not able to prescribe the medication to their patients.

This report addresses these barriers and makes recommendations to the Minister - but there are many more areas that need investigation and improvement including:

- the provision of assessment and treatment for children
- the effective use of social prescribing
- the coordination of support for all neurodivergent individuals in the Island and
- funding for charitable organisations working in this area.

The Key Recommendations of this report are 1, 3 and 6, and the Panel strongly urges the Ministers to consider these along with its other recommendations. These key recommendations concern:

- the implementation of a training programme for nurses to allow them to issue repeat prescriptions, and the establishment of a **support hub for ADHD patients**
- providing those on the waiting list **clear, consistent information** on the status of the potential duration of their wait for diagnosis and treatment to support their wellbeing, and
- the urgent continuation of discussions with primary care providers, and the development of **alternative prescribing pathways** that will alleviate the pressure on the current hospital team, and **reduce the waiting list**, allowing patients to access vital care and support more quickly.

As a community we must continue to evolve and embrace differences of all kinds – different neurotypes included. This must happen in workplaces, schools, health and care settings, homes, and across all our Parishes. This is not just in the interests of fairness and inclusion – but also because those who think differently have the power to add so much value to all of these settings and to excel at the path they choose.

We heard about the amazing benefits that ADHD brains can bring to schools, homes and workplaces. The ability to 'hyperfocus' for hours on an area of interest and to see details others may miss, exceptional problem-solving skills, a creative approach, an ability to see the 'big picture' and identify themes and links, a source of unique ideas and a level of resilience forged through the challenges they have faced. Different does not mean 'less than'.

There are several organisations in this area doing advocacy work and providing services, who gave evidence to the panel. I am grateful to them for taking the time to do so and for answering follow-up questions. I have been hugely impressed by the work that they are doing and the courage they show. There is a thriving and growing neurodivergent community in Jersey and I urge the Government of Jersey and philanthropic individuals/groups to direct resources to these organisations so that they can continue and expand their excellent, and very necessary, work.

I would also like to thank my panel members and panel officers for their hard work on this review, and the Ministers, departmental officers, and all health practitioners and experts who engaged with the review. Finally, I am hugely grateful to the members of the public who wrote to the panel and came in to meet us in person to share some very personal and moving testimonies.

Deputy Louise Doublet
Chair, Health and Social Security Scrutiny Panel

Executive Summary

The Panel launched its review into the prescription of medication for Attention Deficit Hyperactivity Disorder (ADHD) on 9th July 2024. This decision followed on from a Quarterly Hearing with the Minister for Health and Social Services in March 2024. During that hearing, the Panel was advised by the Director of Mental Health and Adult Social Care that due to Jersey's prescribing regulations and the way medicines are funded, the prescribing of ADHD medication can only be carried out by a specialist consultant psychiatrist. The Panel noted that this was contrary to other jurisdictions where initial assessments and treatment are initiated by a specialist and, following that, GPs (General Practitioners) prescribe routine treatment. In addition, due to global medication shortages, Health and Community Services had been 'forced' to issue patients with only one month's worth of medication at a time, instead of the normal 6-week/3-month dose. As a result of these issues, the one consultant psychiatrist available on Island was spending an "extraordinary amount of their time just doing repeat prescriptions". The Panel also learned that medication for ADHD was not subsidised by the Health Insurance Fund (HIF) as the medication did not form part of the approved prescribed list of medication.

The Panel found that during the course of undertaking this review, a number of key themes became apparent from written submissions from members of the public. One area which was most commented on was the long waiting list from referral to diagnosis (3 and a half years). The Panel was informed via these written submissions, that the wait for a diagnosis was having a negative impact on people's wellbeing, with a number of people stating that they felt they had little choice other than to seek private treatment at their own cost, rather than wait so long. The waiting list for assessment and diagnosis of ADHD is arranged in chronological order and is not prioritised for those who may be in need of a diagnosis more than others.

Following further investigation, the Panel believed the lengthy waiting list was linked to there being only one on-Island psychiatrist who had responsibility for both assessment/diagnosis and the prescribing of ADHD medication. The Panel learned that this was due to Jersey's prescribing law which states that ADHD medication can only be prescribed by a specialist consultant which was contrary to other jurisdictions where initial assessments and treatment are initiated by a specialist and, following that, GPs (General Practitioners) prescribe routine treatment.

The Panel was informed that recruitment for specialists in these areas was extremely difficult both in Jersey and the United Kingdom (UK), however, a nurse had been seconded to undertake work on the heavy waiting list which was hoped could alleviate the pressure.

A global shortage of ADHD medication was resulting in ADHD patients being given 1 month's supply of medication as opposed to the usual 3 months, with some reporting that they were constantly worried that the community or hospital pharmacy would run out of their designated medication, and they would be left without. The Panel was given an example where ADHD patients had borrowed ADHD medication from another ADHD patient rather than go without. However, it was noted that the global shortage was outside the control of the Government, and it was hoped this would have eased by the end of 2024. The Panel received a letter from the Minister for Health and Social Services where it asked about the current status of the global shortage. It was informed that whilst for some products the situation had eased, there was still a range of products where the shortage was so severe that Health and Community Services were having to work hard to maintain the treatment of people who were already prescribed those medications. The letter further informed that

'it was very difficult to put a timescale on resolution of the problem, because, when the issue first arose last year (2023), it was expected to be resolved within months. The resolution date has continually been pushed back. So, at the moment, we cannot be certain.[1]*'*

The Panel was made aware that ADHD medication was not on the Prescribed List of Medication approved by the Minister for Social Security, and as a consequence, was not eligible for subsidies from the Health Insurance Fund (HIF). It was further made aware that should ADHD medication be included on the Prescribed List of Medication, it would result in an additional £800,000 per annum which would need to be made available from the HIF. The Panel understands that ADHD medication had not been included in a large part due to the global shortages, however, will monitor this in 2025.

Whilst not part of its Terms of Reference, the Panel understands that a Shared Care Pathway is in discussion with both the Minister for Health and Social Services and the Minister for Social Security. The Shared Care Pathway would allow treatment to be initially assessed by a GP and moved onto secondary care to be initiated. It is hoped that this protocol will allow GPs to issue repeat prescriptions for ADHD medication however, the Panel understands that some GPs are reluctant to sign up to the agreement and until the Shared Care Pathway protocols are agreed, it is difficult to see how primary care will form part of the overall management of patients with ADHD.

Note – at the time of finalising this report, the Panel received the following submission from the Primary Care Board (PCB):

"*At the recent PCB AGM, members were asked whether they feel it appropriate to take on the prescribing of medication for patients with ADHD and the 'unanimous' majority rejected the idea of shared care prescribing at present. The use of secondary care non-medical prescribers and the option of contracting a community pharmacy to dispense medication could improve access to treatment*"

The Panel notes that this position differs from submissions received from individual GPs, and reinforces the Panel's assertion that the Minister for Health and Social Services should actively engage with the PCB to establish an effective working relationship going forward.

Recommendations 1, 3 and 6 of this report are key, and the Panel strongly urges the Ministers to consider these along with its other recommendations. These key recommendations concern the implementation of a support hub for ADHD patients with specially trained staff in place to offer advice, providing a clear communication plan for those on the waiting list and the urgent continuation of discussions with primary care providers regarding the development of alternative prescribing pathways that will help alleviate the pressure on the current crisis being faced.

[1] Letter from Minister for Health and Social Services – 22nd November 2024

Findings and Recommendations

Findings

FINDING 1

Repeat prescriptions for ADHD medication provided under Health and Community Services can only be issued by a psychiatrist. The Panel learned that there is currently one on Island psychiatrist and was informed that the psychiatrist was spending the majority of their time issuing repeat prescriptions.

FINDING 2

Health and Community Services have tried to recruit nurses who are specialised in ADHD and can provide a diagnosis, however, they are extremely rare. In addition, most nurses with this specialised skill may not feel fulfilled in writing 300+ prescriptions per month – the current caseload.

FINDING 3

Health and Community Services have discussed the possibility of training an existing nurse to issue prescriptions, however, this has yet to be determined.

FINDING 4

ADHD medication is not on the Prescribed List of Medications due to global shortages and is not currently eligible for subsidy from the Health Insurance Fund (HIF).

FINDING 5

In addition to the one on Island consultant psychiatrist being authorised to issue repeat prescriptions for ADHD medication provided under Health and Community Services, they are also the only person who can provide an ADHD diagnosis.

FINDING 6

A nurse from the Health and Community Services Department's education team has been seconded to assist with the ADHD waiting list who is also qualified to assess for ADHD diagnosis. The secondment of the nurse is due to be reviewed with a discussion as to how to use the services of the nurse going forward.

FINDING 7

The current waiting list from referral to a diagnosis of ADHD is 3 and a half years. The number of adults on the waiting list is currently at 778, a reduction from 817 in June of this year. The Panel was informed that this was due to the work undertaken by a nurse who had been seconded to work on the waiting list.

FINDING 8

The lengthy waiting list was having a negative impact on the wellbeing of those waiting to be assessed/diagnosed.

FINDING 9

Lack of communication from Health and Community Services whilst on the waiting list was having an impact on the wellbeing of those waiting for an assessment/diagnosis.

FINDING 10

The hospital pharmacy opening hours are Monday to Friday, 9am to 5pm and the Panel learned from members of the public that at times, these impact on the working day. The Panel also learned from members of the public that the waiting area for collection of ADHD medication within the hospital is inadequate for those with who are neurodiverse and/or with neurological illnesses, with reference to poor lighting, the lack of seating and loud Tannoy announcements.

FINDING 11

The waiting list for assessment and diagnosis of ADHD is arranged in chronological order and is not prioritised for those who may be in need of a diagnosis more than others. In addition, it is possible that some people on the waiting list could be suffering from a different neurological condition other than ADHD.

FINDING 12

The Panel learned that there was a global shortage of medication, as a consequence prescriptions for ADHD medication were being issued for one month as opposed to 6 weeks/3 months.

FINDING 13

The Panel learned that there was a danger that due to the global shortage of medication, patients may have to go without their standard medication and substitute it for another product with the same characteristics. Although this had not happened in Jersey, it had happened in other jurisdictions.

FINDING 14

Should ADHD medication be included on the Prescribed List of Medications, the cost per annum would be an additional £800,000 which would need to be subsidised by the Health Insurance Fund.

FINDING 15

The Minister for Social Security informed the Panel that she has reliance on the expert advice from the Pharmaceutical Benefit Advisory Committee (PBAC) and informed the Panel that any decisions could not be made without that expert advice.

FINDING 16

The Pharmaceutical Benefits Advisory Committee (PBAC) meet quarterly and provide recommendations to the Minister for Social Security on medications which should be included/excluded on the Prescribed List of Medication. This list qualifies medicine to be subsidised under the Health Insurance Fund (HIF).

FINDING 17

The Panel understands that a Shared Care Pathway is in discussion with both the Minister for Health and Social Services and the Minister for Social Security. The discussions involve the Shared Care Pathway allowing a referral to be made by a GP and moved onto secondary care to for diagnosis and treatment, following which it would be moved back to the GP for ongoing monitoring. Until the Shared Care Pathway protocols are agreed, it is difficult to see how primary care will form part of the overall management of patients with ADHD.

FINDING 18

The Panel understands that some GPs from small practices are reluctant to sign up to the Shared Care Pathway due to the responsibility of prescribing ADHD medication on a day-to-day basis and not having the flow of patients to gain the experience required.

FINDING 19

Following the written submissions from members of the public, the Panel learned that to have GPs prescribe repeat medication would be of benefit and may ease the existing pressure on the one psychiatrist.

FINDING 20

The Department of Health and Community Services is currently discussing with GPs the possibility of them undertaking special interest sessions in some services – one being ADHD. If a GP was particularly interested in an area and wanted to develop some expertise, the GP could work in that area and receive supervision from the specialist which would increase capacity and help with the service.

FINDING 21

Shared Care Pathways are used successfully in Jersey, however, do not cover mental health issues. In the UK, they successfully cover areas such as mental health, cancer and chronic conditions such as diabetes. The benefits of Shared Care Pathways include patient satisfaction, efficiency and cost savings and better health outcomes.

FINDING 22

The Minister for Health and Social Services and the Minister for Social Security hold different roles with regards to the health service. It is uncertain which Minister would have responsibility for the Shared Care Pathway, or if the role would be shared.

FINDING 23

The Minister for Social Security informed the Panel that one Minister with sole responsibility for the Shared Care Pathway is not something that she would be opposed to.

FINDING 24

Awareness of ADHD is not as prominent as it should be. The Panel was informed that this was due to it being an evolving situation and areas needed to be resolved prior to undertaking raising awareness.

Recommendations

RECOMMENDATION 1

The Minister for Health and Social Services should implement a training programme for nurses to provide them authorisation to issue repeat prescriptions for ADHD medication to ultimately establish a clinic or hub for ADHD patients to pick up medication and receive advice. A costed update should be provided to the Panel within 3 months of publication of this report.

RECOMMENDATION 2

The Minister for Health and Social Services must consider the allocation of duties to the nurse to enable assessments and diagnosis to alleviate the pressure on the one on Island psychiatrist. This should be implemented following review of the secondment, due to take place imminently.

RECOMMENDATION 3

The Minister for Health and Social Services should ensure there is clarity on the status of the waiting list for those currently waiting for an assessment/diagnosis. In addition, clear lines of communication must be available to those who have been referred. This should be implemented within 3 months of the presentation of this report.

RECOMMENDATION 4

The Minister for Health and Social Services should, in conjunction the Minister for Infrastructure, should ensure a modified waiting area be included as part of the new hospital. This should be in line with best practice for waiting areas for those with neurological conditions.

RECOMMENDATION 5

The Minister for Social Security should consult further with Pharmaceutical Benefits Advisory Committee (PBAC) regarding the inclusion of ADHD medication on the Prescribed List of Medications. Due to the rising number of adults requiring ADHD medication, costings should be provided for the next 5 years to ensure its affordability. Discussion on this should be without delay with possible inclusion on the prescribed list by the end of Q2 2025.

RECOMMENDATION 6

The Minister for Health and Social Services, together with the Minister for Social Security must continue its discussions with the Primary Care Board to find a solution to additional medical professionals being authorised to prescribe medication. Should this not come to fruition, both Ministers should implement an alternative plan to offer training to existing medical professionals to qualify for prescribing.

RECOMMENDATION 7

The Minister for Health and Social Services should explore the option of funding GPs to undertake special interest sessions in ADHD, where they would receive training and supervision from the ADHD specialist, helping to increase capacity and alleviate pressure on the waiting list for assessment/diagnosis. This should be carried out by Q2 2025 with an update provided to the Panel of its progress within 3 months of the presentation of this report.

RECOMMENDATION 8

The Minister for Health and Social Services, together with the Minister for Social Security, should discuss roles and responsibilities with a view to one Minister (or Assistant Minister) having sole responsibility for the Shared Care Pathway. These discussions should take place in line with the timeline for the implementation of the Shared Care Pathway with an update provided to the Panel within 3 months of presentation of this report.

RECOMMENDATION 9

The Minister for Health and Social Services, together with the Minister for Social Security, must consider a programme of activity to support ADHD Awareness Month 2025. This should be carried out within ample time for preparation for the next ADHD awareness month.

Introduction

Background and context

Attention-Deficit and Hyperactivity Disorder (ADHD) is a developmental disorder marked by persistent symptoms of inattention and/or hyperactivity and impulsivity that interfere with functioning or development. Stimulants are the best and most common form of medication to treat ADHD and work by increasing the levels of chemicals (neurotransmitters) in the brain. The medication works in different ways, depending on the type.

Symptoms usually begin in childhood and can affect daily life, including social relationships and school or work performance. ADHD is well-known among children and teens, but many adults also have the disorder.[2]

The Panel launched its review into prescription of medication for ADHD on 9th July 2024. This decision followed on from questions and responses on ADHD at a Quarterly Hearing with the Minister for Health and Social Services in March 2024.

The Panel was informed that there were 736 adults in Jersey on the waiting list for an ADHD diagnostic assessment with a wait time of 3 and a half years. The Panel learned that due to Jersey's prescribing regulations and the way medicines are funded, the prescribing of ADHD medication can only be carried out by a specialist consultant psychiatrist. The Panel noted that this was contrary to other jurisdictions where initial assessments and treatment are initiated by a specialist and, following that, GPs (General Practitioners) prescribe routine treatment. It should be noted that there is 1 on Island specialist consultant psychiatrist and that same specialist consultant psychiatrist also carries out diagnosis in the Island. It was further advised that, consistent with international pressures, Jersey faced increases in demand for the service coupled with difficulties in recruiting specialised consultants. It was also made aware of the global shortage of ADHD medication which meant that Health and Community Services were unable to issue prescriptions for more than 1 month (as opposed to the usual 3). As a result of these issues, the one consultant psychiatrist available on Island was spending an "extraordinary amount of their time just doing repeat prescriptions".

To try to address the existing problems with the wait for a diagnosis, the Panel was advised that a Shared Care Pathway, which could enable joint prescribing of ADHD medication with GPs, was being explored by the Minister for Health and Social Services together with the Minister for Social Security.

The Panel has focused its review on the prescription of ADHD medication in adults. It should be noted that that the Panel had agreed to undertake a review on ADHD diagnosis in a much wider context, however, following discussions with Government and a potential overlap of work Government was due to undertake on the neurodiversity strategy, it has agreed to focus on prescription of medication.

The Panel asked the Minister for Health and Social Services for an update on the work being undertaken and was informed that they were on target to have a final draft completed by the end of the year which will collate the 500+ responses to the Survey and 44 attendees at the open events held across the Island. It was further informed that the multi-agency steering group was due to meet in December to finalise the strategy, for submission to the Minister for review.

[2] Attention-Deficit/Hyperactivity Disorder - National Institute of Mental Health (NIMH)

It should also be noted that during the Panel's evidence gathering, it became apparent that there were a number of other issues that arose which needed further investigation, however, were outside of the Panel's Terms of Reference. These are included briefly within this report under the following headings

Appendix 2 – Social Prescribing and Alternative Support

Appendix 3 – Statistics in Jersey versus Statistics in the United Kingdom

This report looks at the key areas the Panel found consistent through written submissions and areas where the Panel believes improvements could be made.

Methodology

Following the launch of its review, the Panel issued a call for evidence asking key stakeholders and members of the public for input. It also held a number of meetings with members of the public and other key stakeholders with an interest in ADHD. Whilst these meetings were held in private, the Panel has had permission to use some of the information obtained during these meetings which are contained within this report.

The Panel received in excess of 30 submissions which were from members of the public, private practitioners, community pharmacists and GPs. The submissions can be viewed in full following this link.

The Panel also held Public Hearings with the Minister for Health and Social Services and the Minister for Social Security. Both can be accessed using the links below.

Public Hearing with Minister for Social Security – 14th October 2024

Public Hearing with Minister for Health and Social Services – 16th October 2024

The Panel also wrote to both Ministers with key questions that it believed would help formulate its review – both letters from the Panel together with the responses from each Minister can be viewed below.

Letter from Panel to Minister for Health and Social Services – 14th August 2024

Letter from Minister for Health and Social Services to Panel – 3rd September 2024

Letter from Panel to Minister for Social Security – 14th August 2024

Letter from Minister for Social Security to Panel – 3rd September 2024

Letter from Panel to the Minister for Health and Social Services – 11th November 2024

Letter from Minister for Health and Social Services – 22nd November 2024

Access to Medication

Who can prescribe

Due to Jersey's prescribing regulations and the way medicines are funded, the prescribing of ADHD medication together with any repeat prescriptions can only be carried out by a specialist consultant psychiatrist. This is contrary to other jurisdictions where initial assessments and treatment are initiated by a specialist (consultant psychiatrist) and following that, GPs prescribe routine treatment and issue repeat prescriptions. In addition, due to global medication shortages, Health and Community Services has been 'forced' to issue patients with only one month's worth of medication at a time, instead of the normal 6-week/3 month dose. As a result of these issues, the one consultant psychiatrist available on Island was spending an *"extraordinary amount of their time just doing repeat prescriptions*".[3]

The Panel questioned the Minister on the impact of having one psychiatrist undertaking both diagnosis and treatment for this condition and asked if consideration had been given to recruiting other specialists to issue repeat prescriptions. It was informed that a second mental health pharmacist post remained unfilled, and recruitment of specialist mental health prescribing pharmacists were extremely rare – both in Jersey and the United Kingdom (UK). It was also informed that recruitment agencies had been contacted by the Department to obtain a nurse prescriber for ADHD medication. However, as this was a specialist skill, the Panel was informed that it was not considered as an 'attractive role' to a nurse who was specialised in an area, training to be a prescriber, as a major part of the role was to write 300 prescriptions a month.

The Panel went on to ask what additional work was being undertaken to help alleviate the pressure and appoint additional specialised staff.

Deputy P.M. Bailhache:

> *So there are not enough psychiatrists at the moment to carry out the necessary prescriptions, is the long and short of it?*

Director of Mental Health, Social Care, and Community Services:

> *So we prescribed for 300 in adult services. We are currently prescribing for 300 patients a month. Now, routinely, we would not be prescribing every month for people, but that is one of the things that we have put in place in order to manage the lack of medication. So, rather than giving people large amounts of 3 months' worth of medication, for example, and then some people not being able to have any, we have limited supply down to one month at a time, which means that we need to prescribe every month, therefore the current psychiatrists in the service are prescribing for 300 people each month.*

Deputy P.M. Bailhache:

> *Is any consideration being given to the appointment of a specialist pharmacist prescriber who could prescribe for repeat prescriptions?*

Director of Mental Health, Social Care, and Community Services:

> *We advertised and recruited to a specialist mental health pharmacist who is a prescriber. It took us the best part of a year and a half from advertising the post to get*

[3] Quarterly Public Hearing with the Minister for Health and Social Services – 14th March 2024

someone into that post. We have a second mental health pharmacist post that is unfilled that we have covered by locums over a period of time. This is an area where specialist mental health prescribing pharmacists are like hen's teeth. They are very rare. The Acting Director of Pharmacy Services may wish to elaborate.

Acting Director of Pharmacy Services, Jersey General Hospital:

Well, only just to confirm, yes, it is extremely difficult to get locums with the kind of skills that you want to take on those roles.

Deputy P.M. Bailhache:

Has any thought been given to having nurse prescribers to help alleviate the pressure?

Director of Mental Health, Social Care, and Community Services:

Certainly has. So we have tried on a couple of occasions with agencies to obtain a nurse prescriber to come and prescribe. Again, nurses cannot just prescribe anything. Prescribing in this area is a specialist skill. You have to prescribe within your scope of knowledge and practice, so you need a nurse who has a good understanding of ADHD and treatment of ADHD. They are quite rare. But then on top of that, the job, the feedback that we have had when we have spoken to people is the job is not particularly attractive. If a qualified nurse has spent their time specialising in an area and training to be a prescriber, to ask them to come and write 300 prescriptions a month is probably not something that they are going to be jumping at. So, we have never had anyone take up that opportunity when we have offered it. We have been talking more recently about, if we put an additional post into this service, whether, if we could not get a nurse prescriber, for example, but we could get a nurse, we could train them to prescribe. So, it may be an area where we need to grow people's skill set.[4]

The Panel also heard from key stakeholders such as ADHD Jersey and one private practitioner who believed it a good idea that nurses be trained to prescribe, and a clinic or hub be set up to allow ADHD patients to pick up medication and receive advice. Both believed that a clinic or hub would help alleviate the pressure on the situation as it currently stood. The Panel also heard that some of these clinics/hubs involved practitioners and pharmacists having group exchanges of information which allowed them to understand the current ADHD environment from both a practitioner and a pharmacist view. This in turn gave them the opportunity to use this information and feed back to their patients, as necessary.

FINDING 1

Repeat prescriptions for ADHD medication provided under Health and Community Services can only be issued by a psychiatrist. The Panel learned that there is currently one on Island psychiatrist and was informed that the psychiatrist was spending the majority of their time issuing repeat prescriptions.

FINDING 2

Health and Community Services have tried to recruit nurses who are specialised in ADHD and can provide a diagnosis, however, they are extremely rare. In addition, most nurses with this specialised skill may not feel fulfilled in writing 300+ prescriptions per month – the current caseload.

[4] Public Hearing with the Minister for Health and Social Services – 16th October 2024

FINDING 3

Health and Community Services have discussed the possibility of training an existing nurse to issue prescriptions, however, this has yet to be determined.

RECOMMENDATION 1

The Minister for Health and Social Services should implement a training programme for nurses - to provide them authorisation to issue repeat prescriptions for ADHD medication with a view to ultimately establish a clinic or hub for ADHD patients to pick up medication and receive advice. A costed update should be provided to the Panel within 3 months of publication of this report.

The Prescribed List for Medication

The Prescribed List of Medication contains details of medication that can be dispensed in the community and reimbursed from the Health Insurance Fund (HIF). At this stage, ADHD medication does not form part of the prescribed list and is not subsidised under the HIF due to global shortages and other considerations. Recommendations are made to the Minister for Social Security for inclusion/exclusion to the list by the Pharmaceutical Benefit Advisory Committee (PBAC). Global shortages of ADHD medication and the role of the PBAC are discussed in more detail later in this report.

FINDING 4

ADHD medication is not on the Prescribed List of Medications due to global shortages and is not currently eligible for subsidy from the Health Insurance Fund (HIF).

Who can dispense

ADHD medication can be dispensed by community pharmacies across the Island and via the hospital pharmacy. However, the hospital pharmacy can only dispense medication which has been prescribed within the hospital by an ADHD specialist. Medication obtained from community pharmacies has a cost associated with it (if not covered by the HIF) whereas that obtained via the hospital does not. As previously mentioned, ADHD medication is not included on the Prescribed List of Medications and is not funded via the HIF.

Who can diagnose ADHD

Only a registered psychologist or psychiatrist can diagnose ADHD in Jersey. Currently there is one registered Government funded psychiatrist on the Island who offers this diagnosis. In addition, there are a number of private clinics with qualified psychologists or psychiatrists in Jersey who offer diagnosis however, these are not funded by Government and must be paid for privately. As mentioned previously in this report, the Island psychiatrist also issues repeat prescriptions which currently cannot be issued by GPs.

During its Public Hearing with the Minister for Health and Social Services, the Panel asked what additional staff, other than the psychiatrist, were available within the ADHD services. It was informed that in addition to the psychiatrist there was a junior doctor, and both the psychiatrist and the junior doctor split their time between ADHD and autism services.

The Panel recalled during its call for evidence of being informed of a nurse who had been seconded to the ADHD team however, it was further informed that the nurse had been

seconded to help only with work on the waiting list. It was not clear what the work involved and the Panel did not go into further detail on this.

The Panel asked if the nurse was qualified to undertake assessments and was informed that she could, but was not doing so at the moment, however, the secondment was due to be reviewed in order to best utilise the nurse's services.

Deputy L.M.C. Doublet:

> *Previously there was mention of a nurse who was seconded. Was that for assessments or prescribing?*

Director of Mental Health, Social Care, and Community Services:

> *So to help manage the waiting list, she is not doing any assessments yet. She can do. She is able to. We are about to review her secondment and think about how do we use her moving forward. Because she is a specialist in this area. Her substantive employment is in the education centre. She is one of the lecturers in nursing. But she is currently spending some time with us helping with this service.*[5]

FINDING 5

In addition to the one on Island consultant psychiatrist being authorised to issue repeat prescriptions for ADHD medication provided under Health and Community Services, they are also the only person who can provide an ADHD diagnosis.

FINDING 6

A nurse from the Health and Community Services Department's education team has been seconded to assist with the ADHD waiting list who is also qualified to assess for ADHD diagnosis. The secondment of the nurse is due to be reviewed with a discussion as to how to use the services of the nurse going forward.

RECOMMENDATION 2

The Minister for Health and Social Services must consider the allocation of duties to the nurse to enable assessments and diagnosis to alleviate the pressure on the one on Island psychiatrist. This should be implemented following review of the secondment, due to take place imminently.

Problems with receiving diagnosis

During its call for evidence, the Panel heard from a number of stakeholders who felt due to the long waiting list, they had little choice other than to seek a private consultation for a diagnosis, at their own expense.

Written Submission – Julie Morgan

> *I am writing to you as a parent of an adult suffering with ADHD who still lives at home. My daughter has been waiting on the list now for over two and a half years. In desperation she had a private consultation which she was diagnosed with ADHD however she cannot afford the private medication so has to carrying on waiting on the list, when she was originally placed on the list she was advised it would be a year and has tried several anti-depressants to try and manage it to no avail after a year she went*

[5] Public Hearing with Minister for Health and Social Services – 16th October 2024

> *to her doctor to confirm she was on the list and then was told the goal posts had moved and she could be waiting up to 3 years. All she needs is the mood stabilising medication used for ADHD but has to wait.*[6]

Anonymous Submission – Anonymous 14

> *Due to the ridiculously unacceptable government based waiting list, my experience has been quite stressful, costly and only seems to be getting worse due to government decisions. This has not helped with me understanding my diagnosis or taken into account what challenges those with ADHD and Autism face. I have paid for the initial ADHD and ASD combined diagnosis, I have and continue to pay for a private psychiatrist which has now relaxed to 4 half session appointments over the year.*[7]

Anonymous Submission – 5

> *As a parent I well understand the frustrations and issues, my daughter is in the UK at university and our only practical solution has been to pay for private prescriptions which is expensive and therefore I'd welcome improvements.*[8]

The Panel asked what, if anything, could be done to assist those who were stretched financially due to the long waiting list for a diagnosis. The Minister for Health and Social Services informed the Panel that subsidising private consultations could set a dangerous precedent, and it was hoped a successful agreement on the proposed shared care arrangements could start to ease the situation. The Panel also asked the question of the Minister for Social Security, querying if funding could be obtained from the HIF for this purpose. The Panel was informed that the HIF was set up to support the costs of people visiting general practice and the Health Insurance Law very specifically says that it has to be a general practice service that is provided.

Associate Director - Public Policy:

> *Can I just make a point about the Health Insurance Fund, because I think you are asking these questions outside our remit. So the Health Insurance Fund is set up to support the costs of people visiting general practice and the Health Insurance Law very specifically says that it has to be a general practice service that is provided. It cannot be something that is a specialist service. So an ADHD specialist would absolutely not be GP. That is what we are talking about, it is about shared care. The GPs may be like a junior partner in some kind of relationship, but their clinical practice does not extend to ADHD diagnosis to start with, so you could not use the Health Insurance Fund to fund somebody visiting a specialist in ADHD or anything else.*[9]

Obvious Obstacles for Prescribing

In researching its evidence gathering, another of the key themes the Panel found was the main obstacle possibly being within Jersey's prescribing regulations with one person being authorised to prescribe. This the Panel learned, has had a knock-on effect on the waiting list which the Panel was informed is currently at 3 and a half years.

[6] Written Submission – Julie Morgan
[7] Written Submission – Anonymous 14
[8] Written Submission - Anonymous 5
[9] Public Hearing with the Minister for Social Security – 14th October 2024

> ***Director of Mental Health, Social Care, and Community Services:***
>
> *Currently, and I cannot speak for the CAMHS, I do not know the detail of that, but in the adult service, if you are referred today, it is going to be 3 and a half years at the current run rate before you are seen. The longest waiting list in the UK (United Kingdom) currently is 10 years.*[10]

The Panel heard that the number of adults on the waiting list waiting to be assessed stood at 778. This was a reduction from 817 in June of this year which the Panel was informed was due to work being undertaken on the waiting list following the secondment of a nurse to support this work. The Panel also learned that the frequency of medication, being issued due to global shortages and creating a significant amount of work for the prescriber, was a major concern and an obvious obstacle regarding access to medication.

The Panel also learned that as part of a proposed Shared Care Pathway, discussions were currently taking place with the Primary Care Body (PCB) to expand the authority to prescribe ADHD medication which would allow GPs to prescribe via a shared care protocol approved by PCB members. The Shared Care Pathway is discussed in more detail later in this report.

FINDING 7

The current waiting list from referral to a diagnosis of ADHD is 3 and a half years. The number of adults on the waiting list is currently at 778, a reduction from 817 in June of this year. The Panel was informed that this was due to the work undertaken by a nurse who had been seconded to work on the waiting list.

Impact of any Obstacles on Patient Wellbeing and Overall Health

The Panel asked a number of questions of members of the public during its call for evidence. One question was the impact waiting times for medication, frequency of medication and the ease of accessing medication had on their wellbeing. One member of the public listed the following

> ***Waiting times for medication*** *– stress, frustration, worry on the thought of potentially missing doses – missed doses would impact on symptoms potentially returning – those titrated on higher doses would be at risk of unwanted side effects from missing doses and restarting especially if on long acting medication*
>
> ***Frequency of prescriptions issued*** *– As this is a controlled drug during the titration/monitoring period this is guided by the psychiatrist frequency of prescriptions can differ in the first few weeks – after titration medication is prescribed monthly -*
>
> ***Ease of access (costs, timing, location, etc) for prescriptions and medication*** *- for private prescriptions this has a financial impact. For example, if your dose is 40mg and the pharmacy only has 20mg available you are paying for x2 of the medication plus dispensing fee. (paid just over £200 this month)* [11]

Another member of the public informed the Panel how the long waiting list was having a negative impact on general wellbeing.

[10] Public Hearing with Minister for Health and Social Services – 16th October 2024
[11] Written Submission - Anonymous 7

Anonymous Submission – 12

> *I truly believe that there is not an issue of over diagnosis of ADHD but rather an increased understanding of the condition which is leading to more diagnoses. The current system with significant waiting lists for diagnosis is failing many children and adults in Jersey.*[12]

Anonymous Submission – 14

> *Due to the ridiculously unacceptable government based waiting list, my experience has been quite stressful, costly and only seems to be getting worse due to government decisions. This has not helped with me understanding my diagnosis or taken into account what challenges those with ADHD and Autism face.* [13]

Communication with those on the waiting list was also raised with stakeholders stating the lack of communication was discourteous and unprofessional.

FINDING 8

The lengthy waiting list was having a negative impact on the wellbeing of those waiting to be assessed/diagnosed.

Anonymous Submission - 14

> *I understand that clinicians are hard to recruit and the department is dealing with an unprecedented rise in assessment requests and diagnoses, but it is discourteous at the very least, and feels unprofessional to not communicate with people on their waiting list and in need.*[14]

The Panel raised the issue of communication with the Minister for Health and Social Services at its Public Hearing on 16th October, and was informed that it was not something that the Department believed it was doing correctly and could do better. In addition, the Panel was informed that publishing the waiting times could be a possibility for better communication in the future.

Deputy L.M.C. Doublet:

> *In terms of the waiting list and people waiting for assessment, what kind of communication is there with those people who are waiting for assessment, diagnosis, and treatment?*

Director of Mental Health, Social Care, and Community Services:

> *So people are written to periodically and I think this is one of the things that we absolutely have not got right so far. I think it is been quite erratic. So I think some people have been written to more frequently, some people have not been written to at all.*

[12] Written Submission - Anonymous 12
[13] Written Submission - Anonymous 14
[14] Written Submission - Anonymous 13

Deputy L.M.C. Doublet:

What is the reason for that?

Director of Mental Health, Social Care, and Community Services:

It has just been due to the workload on the service, I think. So I think one of the things that we need to do is put a system in place where we are more routinely advising people where they are in terms of waiting, and I think one of the things that you suggested the other day was publishing waiting times. I think we kind of do that because we seem to be very regularly having to state publicly what the waiting times are and the waiting lists are. But we could proactively do that and make sure that people do understand what the current waiting time is.[15]

FINDING 9

Lack of communication from Health and Community Services whilst on the waiting list was having an impact on the wellbeing of those waiting for an assessment/diagnosis.

RECOMMENDATION 3

The Minister for Health and Social Services should ensure there is clarity on the status of the waiting list for those currently waiting for an assessment/diagnosis. In addition, clear lines of communication must be available to those who have been referred. This should be implemented within 3 months of the presentation of this report.

Hospital Pharmacy

The Panel heard via written submissions from members of the public that it was not always easy to access the hospital pharmacy due to its opening hours being 9am-5pm Monday to Friday. It was suggested that this timeframe could be quite restrictive for people who work during the day to access. The Panel was also informed that the queues and general conditions for waiting at the hospital pharmacy were inadequate for people with ADHD (or other neurodivergent conditions) due to poor lighting, lack of seating and loud Tannoy announcements.

At its Public Hearing with the Minister for Health and Social Services, the Panel asked if there was anything that could be done to modify these opening hours and to help people gain more access, and in addition, if consideration had been given to a safer space for those with ADHD and other neurodivergent conditions to wait. It was informed that changes would need to be made to the way the contracts worked within the pharmacy which would take a considerable amount of time, therefore it was not something that could happen in the near future. It was also stated that with the hospital being an old building, there was little that could be done to modify the existing waiting areas.

Officer, Health and Community Services:

In terms of the opening hours, certainly we have looked at what is possible in the current circumstances. To progress that really we need to change the way the contracts work for people who work within the Pharmacy Department. That is not a short-term thing to do, that would take a significant amount of time and energy to

[15] Public Hearing with the Minister for Health and Social Services – 16th October 2024

progress that so we can start the conversations. That is not something that is going to happen in the near future.

The other issue about the environment for the pharmacy, I agree, it is an old building; it is not an ideal circumstance for people who arrive at the pharmacy. What we have done is worked really hard to make sure that we manage the queues that were in the pharmacy.

Deputy J. Renouf:

With reference to the poor lighting, the lack of seating, loud Tannoy announcements, I am sure you have looked at this but is there no way that you could create a space that is sort of separate for people queuing for this sort of thing?

Officer, Health and Community Services:

Not within the current structure of the Hospital Department there. Obviously when we are thinking about the new hospital plans then that is something that should be part of that planning. But where it is currently at the moment and I am always open to ideas but we have not got a space that we could utilise in the way you have described.[16]

FINDING 10

The hospital pharmacy opening hours are Monday to Friday, 9am to 5pm and the Panel learned from members of the public that at times, these impact on the working day. The Panel also learned from members of the public that the waiting area for collection of ADHD medication within the hospital is inadequate for those with who are neurodiverse and/or with neurological illnesses, with reference to poor lighting, the lack of seating and loud Tannoy announcements.

RECOMMENDATION 4

The Minister for Health and Social Services should, in conjunction the Minister for Infrastructure, should ensure a modified waiting area be included as part of the new hospital. This should be in line with best practice for waiting areas for those with neurological conditions.

The Waiting List

Once a referral has been received, the Adult Community Mental Health Team undertake a screening service to ensure there is sufficient information and that the referral has been made to the correct area. Following successful screening*[17], the referred person will then go onto the waiting list. There is no priority for the waiting list and each referral is added chronologically.

The process was explained to the Panel at its Public Hearing with the Minister for Health and Social Services on 16th October.

[16] Public Hearing with the Minister for Health and Social Services – 16th October 2024

* The Panel is not aware what this screening involves and felt it was outside of its terms of reference to look in more detail into this area.

Deputy P.M. Bailhache:

Can I just follow up the Chair's question on this waiting list? Can I understand a little bit more about the practicalities involved? How do you get on to the waiting list? Do you fill in a form of some kind?

Director of Mental Health and Adult Social Care:

It is a referral, so on the whole we get referrals from primary care, from GPs or from other health services. But people can also self-refer into mental health services. You would then be asked to provide some basic information as to why you believe that you have ADHD and why you feel that you need an assessment from this service; that is then screened. The team look at the initial referral, often we have to go back even to primary care to say: "Can you send us some more information, please, because we are not sure that this is the right place for the referral to come to?" Then once there is enough information received by the service to say, yes, this person needs an assessment for ADHD, they go on to a waiting list. As I said earlier, what we are now doing, which is a new addition to that process, is we are also sending people a screening tool and asking them to fill that in. That gives us a much better idea about what people's needs are and what the issues are before they get seen by us.

Deputy P.M. Bailhache:

When the screening process has taken place the person is put on the waiting list.

Director of Mental Health and Adult Social Care:

That is right.

Deputy P.M. Bailhache:

Are they put on a number 456 or can they go in at 200 if they are ...

Director of Mental Health and Adult Social Care:

Pretty much up until now it is just done chronologically. You are put on the waiting list in the order in which you are referred.[18]

The Panel queried if, due to the long waiting times, adding people chronologically was the best procedure or should those who are considered a priority be moved to the top of the list. It was informed that this was an area that was being monitored and explored however, the downside would be that some people who had been on the list for 2+ years would be at risk of waiting even longer.

Deputy P.M. Bailhache:

You are going to be put at the bottom of the list.

Director of Mental Health and Adult Social Care:

Absolutely. However, as I said earlier, one of the things that we are talking about is, should we not manage that waiting list based on need?

Deputy P.M. Bailhache:

It sounds as if you have got some kind of information which would enable you to prioritise some ...

[18] Public Hearing with the Minister for Health and Social Services – 16th October 2024

Director of Mental Health and Adult Social Care:

> *Totally, totally that. Of course that has a downside for some people. Some people will hear that and will then worry and think, goodness, I have been waiting for 2 years and now there is a risk that I am not going to be seen as a priority and I am going to keep getting knocked down the list. That is the dilemma of managing based upon need in that way. It is a very fair way up until now in terms of you get seen in the order in which you are referred but it is not necessarily clinically the most sensible way of managing the list.*

Deputy P.M. Bailhache:

> *I suppose you could have a rule that people could not be on the list for longer than a specific period of time, so that if they were continually knocked back eventually they would ...*

Director of Mental Health and Adult Social Care:

> *That is when it all starts to get a bit challenging, is it? Yes.*

The Panel was given some background regarding the work that had been undertaken by the nurse that had been seconded, and was informed that excellent work had been done in triaging the waiting list.

Director of Mental Health, Social Care, and Community Services:

> *Clearly, whichever way we dice it, we need more capacity to manage the waiting list. We are in the process of budget setting currently and one of the things that I am having to do is juggle demand and think about where might we put additional resource next year. Clearly, she has done an excellent piece of work triaging the waiting list. She has helped introduce a new screening tool which has been really helpful. So I am hoping that we will continue with that, but I cannot guarantee that.*[19]

In a letter to the Panel from the Minister for Health and Social Services on 3rd September, it was informed that there was planned implementation of ADHD training for staff across mental health services to support with initial mental health screening and potentially reduce 'unnecessary referral' for an ADHD assessment. The Panel questioned the Minister on what would be defined as an unnecessary referral at its Public Hearing on 16th October. The Panel was informed that occasionally blanket referrals are made in mental health and people are referred to a number of services. It was explained that there are occasions when people are referred and it may not be correct to refer them initially to the ADHD service as their symptoms could be assessed more comprehensively by the Community Mental Health Team, for example. The Panel was informed that these would be considered unnecessary referrals as there could be other priority issues that need attention.

Deputy L.M.C. Doublet:

> *Sure, yes. Could I pick up on something, Minister, that was in your letter of 3rd September where you wrote to the panel: "Planned implementation of ADHD training for staff across mental health services to support with initial mental health screening and, potentially, reduce unnecessary referral for ADHD assessment."? Could you outline what you mean by an unnecessary referral?*

[19] Public Hearing with the Minister for Health and Social Services – 16th October 2024

Director of Mental Health and Adult Social Care:

> *This is when someone is referred. Occasionally we get quite blanket referrals in mental health services, so people are referred to a number of services. One of the things that you need to do early doors is work out which is the right service to see someone, particularly when there is such a long waiting list for some services. There are occasions when people are referred and the right thing to do first is not to refer to the ADHD service. You might want someone seen by the Community Mental Health Team, for example, for a routine mental health assessment because there are other things going on. It is not clear that it is ADHD or there are other priority issues that you want to attend to. Occasionally we get referrals that are rejected, so people refer in and we say: "No, this is not an appropriate referral here." Ideally, particularly because there can be a relationship between ADHD and other mental health presentations, we want to make sure that generically mental health staff have a good understanding of ADHD and are able to pick up, when is the right time to do something else, as opposed to just make a referral to the ADHD service?*

Deputy L.M.C. Doublet:

> *Do you suspect that some of the people who are on the waiting list may have different conditions that are not ADHD?*

Director of Mental Health and Adult Social Care:

> *They may. The work that is being done on the waiting list today has not pulled out lots of people, based on the information that is available. But of course that may happen and that would be awful for someone to wait on a waiting list for a long time only for them to pitch up and us to say: "No, sorry, wrong service, you need to go somewhere else."*[20]

FINDING 11

The waiting list for assessment and diagnosis of ADHD is arranged in chronological order and is not prioritised for those who may be in need of a diagnosis more than others. In addition, it is possible that some people on the waiting list could be suffering from a different neurological condition other than ADHD.

The Panel also questioned what work, if any, was being done to concentrate on people who were more severely in need of treatment than others. It was informed that work was being done continuously. It was informed that a piece of work was being currently undertaken looking at the waiting list in detail.

Deputy P.M. Bailhache:

> *The purpose of that introduction was really to ask whether any work is being done in the Department to think about how one can concentrate on those people who are more severely in need of treatment and help and distinguishing them, differentiating them from those who might have a problem but it is not too serious.*

Director of Mental Health, Social Care, and Community Services:

> *Continuously. It is one of the things that we have been really thinking about in terms of how we manage the waiting list moving forward. So I think I have spoken previously to the panel about in some places, so by coincidence only yesterday the organisation*

[20] Public Hearing with the Minister for Health and Social Services – 16th October 2024

that I came from, the N.H.S. (National Health Service) Trust that I came from in Leeds have closed their ADHD waiting list because they have now got 4,500 people on the waiting list, waiting for an assessment, and they have said: "We cannot continue with a waiting list of that volume." The exception is that they are still accepting urgent referrals and you then get into a constitution about what constitutes urgent. We have talked, we know on our waiting list, and we are doing a piece of work at the moment looking at the waiting list in detail, we know that we have people who are significantly, immediately, adversely affected. For example, someone who is not able to engage in education because they need to be treated. We also know that we have some people who are in the 60s and 70s who have been to their GP (general practitioner) and said: "I think I may have ADHD and I would like to be assessed for it." Those 2 positions are quite different. So we are continuously working through in discussion how do we prioritise, do we prioritise based on urgency, do we prioritise based on how people are impeded, those are conversations that we are still working through.

Deputy P.M. Bailhache:

Obviously, it affects waiting lists.

Director of Mental Health, Social Care, and Community Services:

It certainly does and it affects how you manage waiting lists. The thing I would really want to say, of course, is that there are always other services available. So if someone has ADHD and is on a waiting list to be seen, if they are in mental health crisis, for example, there is a mental health crisis service that can assess them and meet their needs, it does not mean that you just wait, but we do have to work out how we prioritise.[21]

Crisis Service

Although the crisis service was outside of the scope of the Panel, it thought it important to mention it following the waiting list to assure that there is help available 24 hours a day, 7 days per week, should it be needed in an emergency.

The crisis service is offered by the Adult Communities Mental Health Team with an emergency number provided which is open 24 hours a day, 7 days per week. In a crisis, it was the aim of the team to see the person in crisis within 4 hours, '*where this is assessed to be clinically indicated. Otherwise, we'll arrange for you to be seen as soon as possible depending on your needs.*'[22]

Deputy L.M.C. Doublet:

So the crisis service, could you just describe that?

Director of Mental Health, Social Care, and Community Services:

So that is the service where people ring up because they are in crisis and we see them within 4 hours in terms of immediate mental health emergency. So there is a good news story in that we have recruited more substantive psychiatrists than we have had in the time that I have been here and we have got another 2 coming. So that is good. But you do need to be a specialist in this area and not just any old psychiatrist can

[21] Public Hearing with the Minister for Health and Social Services – 16th October 2024
[22] Adult mental health

> *come and work in the ADHD service. Because it is such a new and evolving thing, those people are very limited.*[23]

Private Practitioners and Costs

There are a number of private practitioners in the Island which are qualified to diagnose ADHD and prescribe ADHD medication. The Panel learned via written submissions that some people who had been referred by their GP for a diagnosis, felt they had little choice due to the long waiting list but to seek private care.

The Panel learned that an initial consultation could cost as much as £900, and £250 for each follow up appointment topped with medication costs. Private prescription costs varied depending on the medication prescribed, but the Panel heard that this could range from £90 to £300 per month.

The Panel understands that there is a pricing disparity between community pharmacies who dispense ADHD medication and in addition, on average a 30% difference in price between community pharmacies and the hospital pharmacy. The panel learned that this was due to the type of contract pricing that the hospital was able to use as they had access to UK contracts which community pharmacies did not.

The Panel asked if it was possible for community pharmacies to buy in bulk as a collective and was informed that community pharmacists are remunerated from the HIF which is linked into a reimbursement scheme for England and Wales, together with a pricing system. If community pharmacies were to buy in bulk, Jersey would have to set up its own remuneration process which the Panel learned would be quite an undertaking. The Prescribing Officer informed the Panel that community pharmacies will purchase at one price, will be reimbursed at another price, and the difference is their profit margin. The system used to determine the reimbursement price was based on the system for England and Wales. It was also explained to the Panel that there is a fixed price per item which is set by the UK rather than by Jersey, because Jersey do not have the facility or resources to set its own prices.

Deputy P.M. Bailhache:

> *Could this problem be ameliorated if they were to act as a collective and having the benefit of bulk buying?*

Prescribing Advisor:

> *We are tied in, in terms of remuneration for community pharmacists, we link into a reimbursement scheme for England and Wales and a pricing system that is operated through England and Wales. So we would have to effectively set up our own remuneration process, which is quite an undertaking.*[24]

The Prescribing Officer went onto explain how prescriptions are priced and the reason why Jersey was unable to undertake this process.

Prescribing Advisor:

> *So, each year there is about 2.2 million prescription items that are dispensed in Jersey, and each month those prescriptions are sent off-Island to Newcastle to be processed by the N.H.S. (National Health Service) Business Services Authority and they have an operation that deals with all prescriptions from across the U.K., to process them to*

[23] Public Hearing with the Minister for Health and Social Services – 16th October 2024
[24] Public Hearing with the Minister for Social Security – 14th October 2024

> *capture information about who the prescriber is, who has dispensed it, what the medicine is, what the value of that medicine is, with the end result being how much to reimburse community pharmacists for the products that they dispense and the fees that are associated with that dispensing. That is the service that Jersey has bought into for many years, and it is only because of the specialism N.H.S. Business Services that we can use that.*[25]

The Panel understands that further work could be undertaken on the pricing disparity of prescriptions, however, recognises the huge undertaking that this would entail from Health and Community Services.

Global shortage of ADHD Medication

There has been a global shortage of ADHD medication since the end of September 2023. This has been caused by a combination of manufacturing issues and an increase in global demand.

Dr Ulrich Müller-Sedgwick, a consultant psychiatrist for adult neurodevelopmental pathways at the Royal College of Psychiatrists, says production and manufacturing issues are a factor:

> *"There's only a limited number of factories where these medicines are actually produced. They're stimulants, so there's also quite a high security standard in these factories and they're not easy operations to run." The medications are often classed as controlled drugs, which means a maximum of one month's supply can be prescribed at a time. Supplies remain fragile, with some forms of two of the five licensed medicines – atomoxetine and methylphenidate – still affected.*[26]

How long will the shortage last?

Shortages of the various products are expected to resolve at different times between June and November 2024[27]. The Panel learned from its hearing with the Minister for Social Security, that the global shortage was one issue that was restricting ADHD medication being available on the Prescribed List of Medication making it eligible for subsidies via the HIF.

Plans were in place to add ADHD medication to the Prescribed List of Medication however, when the latest list was approved at the end July 2024, ADHD medications were excluded as a result of shortages and other considerations.[28]

At its Public Hearing with the Minister for Health and Social Services, the Panel asked what was being done to try and mitigate the problems faced with the shortage, and how it was being monitored and communicated to pharmacists. It was informed that there was a website which informs practitioners about the availability of certain drugs which is updated every week however, this website is only available to practitioners and pharmacists.

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[25] Public Hearing with the Minister for Social Security – 14th October 2024
[26] ADHD medication shortage: 'We're rationing meds to get by' - BBC News
[27] Shortage of medicines for ADHD (Attention Deficit Hyperactivity Disorder) - Information for patients, families and carers - Updated June 2024 - Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (cntw.nhs.uk)
[28] "National shortages" impact ADHD prescribing plan | Bailiwick Express Jersey

Deputy L.M.C. Doublet:

Okay. So, in terms of the shortages, from the hearing that we had with the Minister for Social Security, we were informed that there was a website that informs practitioners about the availability of certain drugs and that it is updated every week. Is that something that you are aware of and checking?

Acting Director of Pharmacy Services, Jersey General Hospital:

Yes. So that is something we use on a regular basis. The data behind it comes from the Department of Health and Social Care in the UK, so it is the most up-to-date data they have got. It does not always reflect exactly what is available on the ground, and sometimes events overtake it very rapidly. But it is a very useful resource and it is something that we use and we refer to continually.

Deputy L.M.C. Doublet:

Do you have any other sources of information to tell you what the long-term outlook is for these medications?

Acting Director of Pharmacy Services, Jersey General Hospital:

Not really at the moment. So I mean obviously, because it is a global issue, it is not even just a UK issue, it is dependent on decisions made by manufacturers, in some cases by the Drug Enforcement Agency in the USA sometimes. So at the moment it is very difficult to predict and clearly it has been difficult to predict just from what we know of the timelines that have been suggested and then passed.

Deputy L.M.C. Doublet:

In terms of the root causes, is it just that the demand has got so big that production cannot keep up?

Acting Director of Pharmacy Services, Jersey General Hospital:

That is a major part of it. Yes, that is a major part of it, yes. It is also affected by some odd things, like, as I said, the Drug Enforcement Agency in America restricts the supply to manufacturers of certain raw materials and so that can have an impact on what they can produce. It also, in the U.S.A., they restrict supplies to community pharmacies there, which perhaps has an impact then on the way that people access the medication by using online services, which have a more global impact.[29]

What is happening in Jersey?

As discussed previously in this report, Health and Community Services in Jersey is giving out shorter prescriptions due to a global shortage of the ADHD medication.

Stakeholders complained that at times, pharmacies would run out of certain medication leaving the patient without for a time with no security that future prescriptions could be filled.

Anonymous Submission – 6

I have to admit that recent changes to prescribing have been quite stressful, especially when combined with shortages of these drugs. Now, instead of going to the Hospital

[29] Public Hearing with the Minister for Health and Social Services – 16th October 2024

pharmacy, I have had to hunt around various pharmacies to find out who could get hold of the medication. On top of that, I now have to pay for the medication as well. [30]

Anonymous Submission – 8

You have to wait to collect it at least a couple of days and they want you to phone pharmacy prior to collecting it to see if it is ready, I have phoned 6 x in one day and the phone wasn't even picked up due to shortage in staff so when you try the method they want they get really antsy when you just turn up but what else do you do?
My experience was a 7 month wait and when there was a shortage, I know a couple of people that had to go without.[31]

Anonymous Submission – 11

I am aware of worldwide medication shortages. My medication has been affected by the shortage.[32]

The Panel also heard from the Minister for Social Security regarding the global shortages and was informed that in terms of the shortages, there was very little that Government had any control over.

Deputy L.M.C. Doublet:

In terms of the shortages, what you have said is that it is something globally that we do not have any control over. In terms of monitoring it, how is that being monitored and what kind of information do you get about where the drugs are coming from and how much of each drug you can access and are there different places that we can go to get the drugs, et cetera, how does that work?

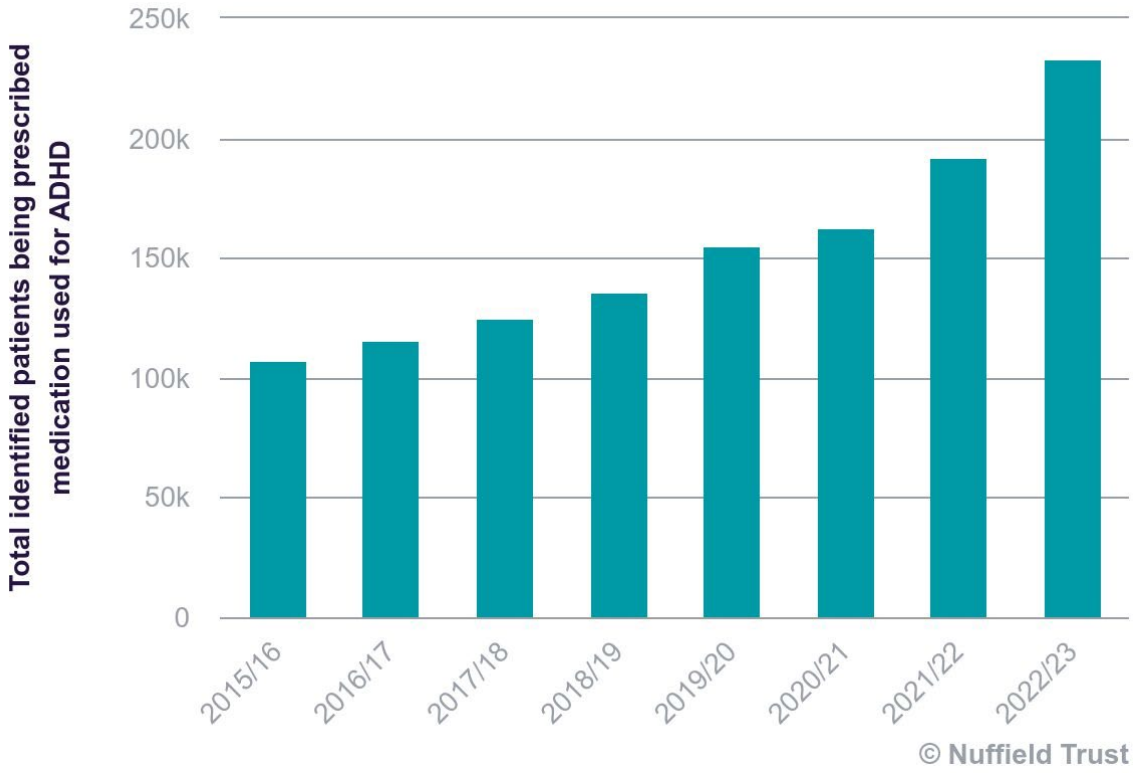
Prescribing Advisor:

I can answer it in terms of from the community perspective. All of the community pharmacists in Jersey obtain their medicines through UK based wholesalers and manufacturers. They face the same challenges in obtaining supplies as they do in the U.K. and are affected by shortages. It is an improving picture and at the minute most medicines for ADHD are now back in adequate supply. There is a handful that still there are some problems with. We monitor that weekly. There are specialist sources of information in the U.K., particularly the Specialist Pharmacy Service[33] *based in the U.K., which publishes updated information every week around medicines' availability.*[34]

The Panel asked what would happen in practice if a prescription for a particular medicine, for a particular patient, was in short supply could not be found. It was informed that fortunately this had not happened in Jersey so far, however, it had been known to have happened in other jurisdictions. The Panel was informed that the solution would be to utilise other products with the same characteristics to treat those without their usual medication, whilst working with prescribers to obtain the necessary products that are needed.

[30] Written Submission - Anonymous 6
[31] Written Submission - Anonymous 8
[32] Written Submission - Anonymous 11
[33] Free of charge but for registered practitioners only
[34] Public Hearing with the Minister for Social Security – 14th October 2024

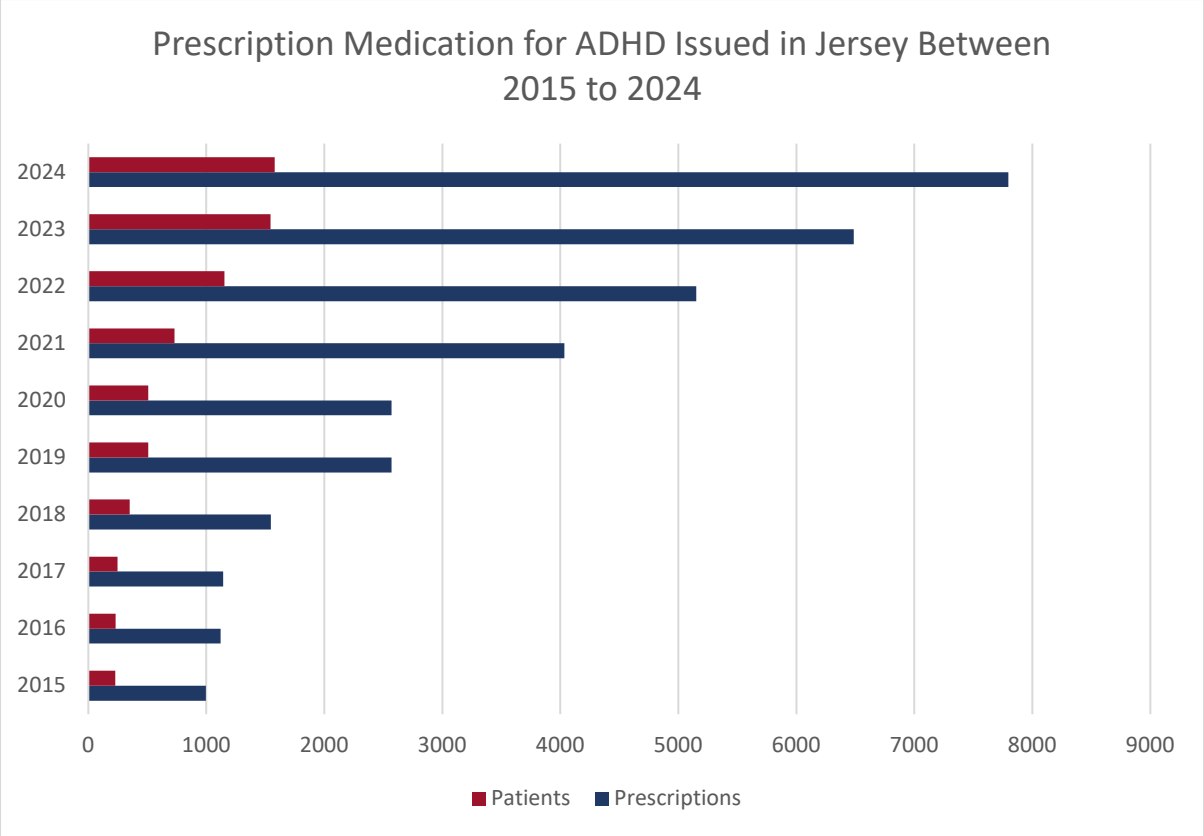
The graph below from Nuffield Trust shows the increase in numbers of patients being prescribed ADHD medication in the UK from 2015/16 to 2022/23. It shows an increase of approximately 110,000 people in 2015/16 rising 235,000 in 2022/23.



The Chart below is information received from the Minister for Health and Social Services in his letter to the Panel dated 22nd November. It shows an increase It shows an increase of approximately 229 patients in 2015 rising to 1580 in October 2024. It also shows an increase of prescriptions rising from 995 in 2015 to 7797 in 2024.

Year	Number of Prescriptions	Number of Patients
2015	995	229
2016	1121	231
2017	1142	247
2018	1546	350
2019	2218	403
2020	2569	507
2021	4034	730
2022	5153	1153
2023	6486	1543
2024 (to Oct 31)	7797	1580

The graph below also shows the increase in prescription medication in Jersey from 2015 to 2024 using the figures supplied by the Minister for Health and Social Services.



FINDING 12

The Panel learned that there was a global shortage of medication, as a consequence prescriptions for ADHD medication were being issued for one month as opposed to 6 weeks/3 months.

FINDING 13

The Panel learned that there was a danger that due to the global shortage of medication, patients may have to go without their standard medication and substitute it for another product with the same characteristics. Although this had not happened in Jersey, it had happened in other jurisdictions.

Conclusion

Whilst the Panel understands that the global shortage in medication is having an ongoing impact on wellbeing for ADHD sufferers, unfortunately it is not something which can be controlled either by the Panel or Government. The Panel received a letter from the Minister for Health and Social Services on 22nd November which provided an update on the status of the global shortage. The Panel was informed that whilst for some products the situation had eased, there was still a range of products where the shortage was so severe that Health and Community Services were having to work hard to maintain the treatment of people who had already been prescribed those medications. It was further informed that

'It is very difficult to put a timescale on resolution of the problem, because, when the issue first arose last year (2023), it was expected to be resolved within months. The resolution date has continually been pushed back. So, at the moment, we cannot be certain.'[35]

The Panel will continue to monitor this situation and, will continue to question both Ministers for updates.

External Influences

The Panel learned of several outside influences who play a part in the health industry in Jersey. The Pharmaceutical Benefits Advisory Committee (PBAC) make recommendations to the Minister for Social Security for inclusion of drugs onto the prescribed list and the Primary Care Board (PCB) are representative of the GP community in Jersey with responsibility for patients wellbeing. These outside influences and their roles are described in more detail in this section.

The Health Insurance Fund (HIF)

The Health Insurance Fund (HIF) was established when the Health Insurance (Jersey) Law 1967 came into force on 4th December 1967. The Fund receives a set proportion (currently 2%) of all social security contributions collected (12.5%) under the Social Security Law. This 2% rate is made up of a 0.8% contribution from employees and a 1.2% contribution from employers. Currently the Fund subsidises patients at £20.28 for each GP visit. In addition to the £20.28, a further subsidy of £30 is paid for each GP visit from the HIF.

The Fund also covers the cost of prescriptions dispensed by community pharmacists.[36]

Medicines covered under the Health Insurance Fund

Medication covered under the HIF are those that form part of the Prescribed List of Medications and are prescribed by GPs as primary care. As ADHD medication is not on the prescribed list, it is not currently subsidised under the HIF. Items available from the Prescribed List of Medications can be found here.

The Panel learned that the cost implications to the HIF, should ADHD medication be included on the prescribed list, were estimated at £800,000 (with a current waiting list of approx. 900 people).

Deputy J. Renouf:

> *It is just a question in terms of the maths of this. If you are currently treating 300, you have got 800, nearly 900 on the waiting list, what are the cost implications in terms of the drug supply for that? You are going to be well over trebling the number of prescriptions for what are relatively expensive drugs.*

Deputy L.M.C. Doublet:

> *I think the estimate was £800,000.*

[35] Letter from Minister for Health and Social Services – 22nd November 2024
[36] Health Insurance Fund (Miscellaneous Provisions) (Amendment) (Jersey) Law 201-: Draft

Director of Mental Health, Social Care, and Community Services:

> *So there was an estimate, given what the cost to the HIF would be, for the people that we are already prescribing for, the cost is coming from the hospital pharmacy, so the cost is already in our runway, it is there. Of course, you are absolutely right, if by magic next week we could assess everyone and everyone requires treatment that is currently on the waiting list, then the number of people that are being treated would treble almost.*[37]

The Panel queried that should ADHD medication be included within the Prescribed List of Medications, how the cost implications of this could be managed. It was informed that currently, spending is just over £17 million per year on prescription medication which is subsidised by the HIF.

Deputy P.M. Bailhache:

> *Can the Health Insurance Fund afford to cope with ADHD prescriptions?*

Prescribing Advisor:

> *I am not sure I am the right person to say whether it could afford it. Certainly it would be quite a substantial additional cost. We estimate, based on the estimated number of patients, about 1,500 patients, and the average cost per year for each treatment, which is about £550 a year. So we are talking in excess of £800,000. To put that in context, we currently spend just over £17 million a year on prescription medicines in the community under the HIF (Health Insurance Fund). To put that £800,000 in context, that is more than we spend on treating infections, on antibiotics and things. So it is quite a substantial chunk of money.*[38]

The Panel also asked the Minister what views were held, if any, regarding the desirability or otherwise of having ADHD medications covered within the HIF. The Minister informed the Panel that whilst she had been following the issue in great detail prior to her role as Minister, speaking with the Prescribing Advisor and the Chair of the Pharmaceutical Advisory Board, it became clear that there were multifaceted layers of complexity around taking that decision.

FINDING 14

Should ADHD medication be included on the Prescribed List of Medications, the cost per annum would be an additional £800,000 which would need to be subsidised by the Health Insurance Fund.

RECOMMENDATION 5

The Minister for Social Security should consult further with Pharmaceutical Benefits Advisory Committee (PBAC) regarding the inclusion of ADHD medication on the Prescribed List of Medications. Due to the rising number of adults requiring ADHD medication, costings should be provided for the next 5 years to ensure its affordability. Discussion on this should be without delay with possible inclusion on the prescribed list by the end of Q2 2025.

The Minister went on to explain that she was satisfied that consideration had been given to the complexities around the decision not to include ADHD medication on the prescribed list at this time.

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[37] Public Hearing with Minister for Health and Social Services – 16th October 2024
[38] Public Hearing with Minister for Social Security – 14th October 2024

The Minister for Social Security:

> *I was quite keen to ensure, and I asked in fact for the Board to provide detailed reasons, because I knew that this is a matter of great public concern and interest. When I did receive the advice last time around, not putting these drugs on the prescribed list, I was satisfied that the Board had given due consideration to all of those complexities. Because, of course, we all want to be in a place where we can resolve the issues. I find that this particular scrutiny review is incredibly helpful because it does draw out, from other perspectives as well, the issues that we are dealing with and also how we need to work together right the way across Government, because we have 3 Ministers involved here, and I think that we are all committed to finding a way that we can resolve the issues. It was just that there are other things that are currently outside of our control, which means that it is not appropriate at this point in time to add it to the list.*[39]

The Panel understands that the main areas outside of the Ministers control are the current global shortage which could add to the already problematic issue of medication on a month by month basis (as opposed to 3 months) and the ongoing discussions with the Primary Care Body regarding the Shared Care Pathway. The Minister also informed the Panel that there is a reliance on the expert advice and decisions could not be made without that advice.

The Minister for Social Security:

> *What would make me feel confident is the advice of the Prescribing Benefits Advisory Committee. I get good advice from that board. As the prescribing advisor said, there are current applications in and the board themselves did say in the last advice to me that in principle they are supportive, so I do not see them as being a blocker. I see it that I will look to the advice that I am being given by experts in that area. It would be foolhardy for me as a Minister to think that I could make that decision without the expert advice.*[40]

FINDING 15

The Minister for Social Security informed the Panel that she has reliance on the expert advice from the Pharmaceutical Benefit Advisory Committee (PBAC) and informed the Panel that any decisions could not be made without that expert advice.

Role of the Pharmaceutical Benefits Advisory Committee (PBAC)

Under the Health Insurance (Jersey) Law, 1967, the PBAC was formed to review medicines and to advise the Minister for Social Security as to what products/medicines should be added or removed from the Prescribed List. The Chair and other appointed members of the Committee hold office for a period of 12 months ending on the twelfth day of April and are eligible to be re-appointed. [41]

[39] Public Hearing with Minister for Health and Social Security – 14th October 2024
[40] Public Hearing with Minister for Health and Social Security – 14th October 2024
[41] Pharmaceutical Benefit Advisory Committee (PBAC): Re-Constitution

The Prescribed List is a positive reimbursement list that determines those medicines and devices that can be dispensed in the community and reimbursed from the HIF. As discussed earlier in this report, ADHD medication does not form part of the Prescribed List of Medications.

In a letter from the Panel to the Minister for Social Security dated 14th August, the Panel asked the Minister for clarification on the process around recommending the addition (or deletion) of a drug to the prescribed list. The Minister, in a response dated 3rd September stated that

'Recommendations for changes to the Prescribed List are made to the Minister for Social Security by the Pharmaceutical Benefit Advisory Committee (PBAC) that meets 4 times each year to consider applications from local health professionals. Such applications can be for products to be added or removed, where for example, they have been discontinued or are considered to be of low clinical value.'

The Minister goes on to say that

'There are examples of medicines, like medicines for ADHD, where, with support, GPs can undertake that long-term prescribing. But it is making sure that GPs are well supported in doing that.'[42]

The Minister also informed the Panel that the PBAC would tend to review any new application in terms of its safety, effectiveness and cost effectiveness. Consideration would also be given around the expectation of the role of GPs and if primary care was the best place for a particular medicine to be prescribed.

FINDING 16

The Pharmaceutical Benefits Advisory Committee (PBAC) meet quarterly and provide recommendations to the Minister for Social Security on medications which should be included/excluded on the Prescribed List of Medication. This list qualifies medicine to be subsidised under the Health Insurance Fund (HIF).

ADHD Inclusion onto the Prescribed List of Medications

Further details of this reasoning behind ADHD medications not being included on the Prescribed List of Medications can be found in the following quotes when the issue was discussed at the Panel's Public Hearing with the Minister for Social Security on 14th October.

Deputy L.M.C. Doublet:

> *We are aware that ADHD medication has been considered for inclusion in the past; is that correct?*

Prescribing Advisor:

> *Yes, we have got application both from the adult psychiatrist, Dr. Müller-Sedgwick, and the Children's and Adolescent Mental Health specialist, Dr. Catherine Keep. They are currently in process.*

[42] Public Hearing with the Minister for Social Security – 14th October 2024

Deputy L.M.C. Doublet:

Thank you. The reasons for those medications not currently being on the approved list, was it because of the shortages, is that the main reason that they are not?

Prescribing Advisor:

At the last meeting of the PBAC (Pharmaceutical Benefit Advisory Committee), the medicines were considered and generally the committee was supportive of the medicines going on to the prescribed list, but, yes, there were concerns expressed at this time around the shortages of a number of medicines that are used in the treatment of ADHD and it was felt that, because of those shortages, it would put the arrangements, what we call shared care arrangements, it would make them difficult to enact because, if patients had to chop and change medicines because of those shortages, it would mean them having to go back to the specialist if there was a change in the medicine needed.

Deputy L.M.C. Doublet:

Okay. Could you list all of the reasons as to why those medications are not on the list, so shortages being one of them, and are there any others?

Prescribing Advisor:

At the moment in time, the shortages was the main concern. I think, in general, there was concern, not concern, but a need to understand the whole pathway around it. It is not simply a case of asking GP's to write on the bottom of a prescription, to sign these, it is about how do we make primary care part of the overall management of patients with ADHD, not simply about who is going to sign the prescription, so there was some uncertainty in PBAC around how that would all work and how that would all fit together in the pathway for patients.[43]

Role of the Primary Care Body (PCB)

The Primary Care Body represents GPs in Jersey and is dedicated to ensuring the highest quality of Primary Care within the Island. The aims of the PCB are:

- To encourage and promote the practice of High Quality Primary Care
- To promote high standards of professional conduct among practitioners
- To encourage and promote the study and development of Primary Care
- To work with other agencies to foster development of health services that ensure patient safety and quality of care

To represent the views of General Practitioners to other organisations or agencies in particular: -

- the administration of the profession
- civil rights or liberties or matters of public interest, or

[43] Public Hearing with Minister for Social Security – 14th October 2024

- the enactment of legislation or the review or reform of existing laws pertaining to Primary Care
- changes to delivery of Primary Care in the future

The PCB meet once per month to discuss ongoing health arrangements for primary care in the Island and liaise closely with the Minister for Health and Social Services together with the Health and Community Services Department regarding the development and implementation of healthcare policies, focusing on improving the quality, efficiency, and accessibility of primary care on the Island. The Panel further understands joint meetings are held with the PCB and the Minister for Health and Social Services. The Panel was informed that the Minister for Health and Social Services has met on several occasions with the PCB since his appointment. Routine meetings between the Minister for Health and Social Services are held with the PCB once a quarter with the Minister for Social Security attending meetings as necessary and when required.

The Panel understands that discussions are currently in place between the Minister for Health and Social Services and the PCB regarding the implementation of a Shared Care Pathway, for ADHD. This is discussed in the next section of this report.

The Shared Care Pathway

Throughout the course of its review, the Panel was made aware of discussions between the Minister for Health and Social Services, the Minister for Social Security and the Primary Care Board regarding a Shared Care Pathway.

A Shared Care Pathway in health services refers to a collaborative approach where multiple healthcare providers work together to deliver coordinated care for patients, often with complex or long-term health conditions. The pathway outlines a series of steps, interventions, and responsibilities that are shared across different care providers, ensuring that the patient receives continuous, appropriate, and high-quality care across various settings. Usually, a patient suffering from a condition gets treatment from a primary care physician. If the patient needs further assessment, they will be referred to a specialist. This is a point of interface between primary and secondary care.

Care pathways assist in clinical decision making by providing criteria regarding diagnosis and treatment that lead to recommended courses of action. They are based on evidence from current peer-reviewed literature and the considered judgment of expert panels. These pathways are updated frequently with new technologies and emerging evidence.[44]

As part of the Shared Care Pathway for Jersey, discussions have been held, and continue to take place, with the Primary Care Body with a view to the prescription of ADHD medication being allocated to GPs. It should be noted that the assessment and diagnosis for ADHD would still need to be given by an ADHD specialist, with GPs having authority to subsequently issue repeat prescriptions. In addition, should a patient with ADHD require a change in medication or further assessment, this would need to be carried out by an ADHD specialist and not a GP.

The Panel asked what the Shared Care Pathway would look like, should it be implemented. It was informed that it would be a treatment which initially is assessed by a GP (in this context, the treatment is always initiated by a consultant in secondary care) but cannot be done wholly by a GP, as they may not have the expertise or clinical knowledge in that area. The treatment would then be moved onto secondary care to be initiated. The Associate Director of Public Policy explained how the pathway would work.

[44] Care Pathway - an overview | ScienceDirect Topics

Associate Director - Public Policy:

> *Should we just describe what a shared care agreement is? It will be a treatment which cannot be done wholly by GP. A GP does not have enough expertise or clinical knowledge to do it on their own, so it is always initiated in secondary care. So you are always going to go to a specialist first of all, you are going to go to secondary care. The secondary care clinician is going to set you up for what you need to do, and if they are happy that you are stable on that treatment, they are then going to share the care with a GP The GP is going to take over the monitoring of that patient and going to continue to prescribe the same drug at the same dose and the same frequency. If the GP, who has got the clinical knowledge to monitor the condition, sees any change in the condition and thinks something might need to be changed in terms of medication, they have to move the patient back into secondary care because it is the secondary care clinician who has to initiate each full treatment. So it is shared between the two, but the GP, we talked before about training or whatever, so the GP needs to have the training to be able to monitor the condition, but is not going to be making a change. So it should always be shared between the 2, so it is sharing it out. So if somebody is very stable, the GP can carry on with it. But, if there is a change or something is not quite right or whatever, has to go back. Just while I am talking, just very quickly on shared care, so we talked about GPs and small practices, you have to also remember that, for the shared care, unless all the GPs feel confident to do it, there will be some patients who will not be able to access a shared care agreement and some patients who will be able to access it, and the last thing to remember in Jersey is if you have a shared care agreement, when you go to your GP you are going to pay for that, if you are going to a hospital clinic it is free. So there are lots and lots of complexities to doing that. When we get past the technical issue as to how to do it and how to create the right training and support for the GPs, there are other things to think about as well. It is just quite a complicated situation unfortunately. That is probably why we are not quite there yet because there is lots and lots of things to think about.*

The Panel learned that there was some resistance from GPs being involved in the prescribing of ADHD medication however, the Minister for Health and Social Services stated in a letter to the Panel that this was something that they were seeking to resolve. The Panel, during its Public Hearing with the Minister, asked for further clarification around the Shared Care Pathway and when it might look to be implemented. The Panel was informed that there were two outstanding issues – the global shortage of medication and the reluctance of some GPs to sign up, however, work was ongoing and it was hoped a solution would be in place as soon as possible.

Deputy J. Renouf:

> *I just think for the members of the public it would be useful to know what schedule you are working to, to develop these shared pathways. When might that bear fruit?*

Director of Mental Health, Social Care, and Community Services:

> *As soon as possible. There are 2 outstanding issues. So the first issue is that we need to agree the protocol with primary care. We have been working on that jointly with CAMHS, so that is a tripartite arrangement essentially. Then it needs to be agreed that ADHD medicines can be prescribed from the HIF, so can be prescribed in primary care. That has been agreed by the group that support that, notionally it has been agreed. But there were 2 conditions, one was that the GPs needed to be happy with the shared care arrangement, and secondly this issue of the drug availability. So, no one wants to sign up to a shared care arrangement and make prescribing potentially more complicated on the Island at the point at which there is a limitation in the amount*

of drugs that are available. But, once that settles, I am hoping that we will be in a position where we can move forward. I do not think every GP practice is keen to do it, I think we have had that feedback really clearly. But we have also heard really clearly from some GP practices that they are really keen to do it and would be happy to take that on. So, yes, as soon as possible.

The Panel asked what the reasons were for GPs being reluctant to take on the role.

Deputy L.M.C. Doublet:

What were the reasons of the GPs that did not want to do it? What were their reasons?

Director of Mental Health, Social Care, and Community Services:

So I think some of that was about being concerned about we are not specialists in this area and we are being asked to take on prescribing of specialist drugs, controlled drugs. But the answer to that I think, where it works well elsewhere, is making sure that people have access to the specialist advice when they need it.[45]

The Panel was also informed that the view from the smaller practices was that they did not see enough patients with the condition to feel comfortable prescribing ADHD medication, and that even if a final version of the Shared Care Pathway was confirmed, it would not be a straightforward solution.

Deputy L.M.C. Doublet:

Yes So, in terms of the GPs, Minister, your letter stated that, even if a final version of a protocol with GPs is confirmed, that some GPs may not feel comfortable to prescribe and have stated that they will decline requests for shared care. You went on to say that GP's are responsible for the prescriptions they issue and the Government cannot require GPs to prescribe a specific medicine or agree to participate in a shared care protocol. So, again, I can see why you are saying it is not a straightforward, simple solution. Can you elaborate, whoever wants to answer this one, why do you think that some GPs would decline requests for shared care?

Prescribing Advisor:

I can make a start. I think largely, and certainly views that we have had expressed back to the PBAC from some GPs, particularly those who are in the small practice, do not feel that they will see enough patients and gain enough experience day-to-day to feel comfortable in prescribing and dealing with queries around medicines for ADHD and they have suggested perhaps in larger practices where they have got more patients, it may be appropriate to have maybe one or two clinicians in those larger practices who have more experience and have done more training to oversee prescribing for ADHD

The Panel was further informed that it was not the part of Government to compel a prescriber to undertake an obligation of prescribing that they were not comfortable with.

Deputy P.M. Bailhache:

Presumably not every GP will be obliged to take part in this process.

[45] Public Hearing with the Minister for Health and Social Services – 16th October 2024

Director of Mental Health, Social Care, and Community Services:

> *We cannot oblige GPs to prescribe anything. You cannot oblige a prescriber to prescribe something that they do not feel competent to prescribe.*[46]

The Panel, during its call for evidence, received written submissions from GPs with some of them explaining the reasons as to why they felt reluctant to move forward with the issuance of prescriptions for ADHD

> ***Jonathan Palmer GP– Written Submission***
>
> *I read the article on the bbc website about a lone psychiatrist doing repeat ADHD prescriptions. I would say this is an optimum example where putting in a specialist pharmacist prescriber in a follow up capacity is probably a worthwhile investment. Lumping it on to GPs is possibly fine but do your GPs have capacity to review and manage those patients? I would be wary of potential consequences.*[47]
>
> ***Anonymous Submission – 5***
>
> *Our position is that we would support the ongoing review of stable patients with ADHD when it is safe and appropriate. However, it's incorrect that lots of GPs do this elsewhere. Some GPs will take on shared care agreements, but many don't. In an increasing number of areas in the UK, GPs have withdrawn support for shared care agreements because the arrangements are unfunded and under supported. The complex supply issues mean that small community pharmacies can really struggle to maintain consistent supplies and it is likely that for now, hospital pharmacy provides the surest route to stable supplies. Not all GPs will be comfortable taking on the complex management of ADHD, these are drugs with significant potential side effects and issues with addiction. The lack of good psychiatric support worries many GPs, we cannot be seen as an easy route to access and service provision because the health department is failing to recruit and retain specialists. GPs are specialists in general medicine and primary care, we are happy to undertake shared care arrangements where the evidence supports this as best practice and providing the highest standard of care. However, seeing us as the solution to a failure to provide a proper service on island isn't appropriate.*[48]

Written Submission – Primary Care Board

> *Expanding the authority to prescribe medication to GPs could be viable with a good supply of ADHD medication and a shared care protocol approved by PCB members. The shared care protocol will provide guidance for GPs to prescribe ADHD medication safely, meaning the number of healthcare professionals who can prescribe significantly increases on the island. If a shared care protocol is accepted by a GP then they will become responsible for prescribing the medication, however, any change in symptoms, side effects, shortage of medication will need to be reviewed by ADHD specialist and not the GP.*[49]

[46] Public Hearing with the Minister for Health and Social Services – 16th October 2024
[47] Written Submission – Jonathan Palmer
[48] Written Submission – Anonymous 5
[49] Written Submission – Primary Care Body

In contrast to the written submissions received above urging caution on GPs being able to prescribe, there were also a number of written submissions that believed it to be a good idea.

Anonymous Submission – 3

> *Develop a Shared Care Pathway with primary care.*
> *Once diagnosed a GP can take over repeat prescriptions.*
> *You could have a nominated GP lead for each Surgery who could be responsible for minor medication changes within a protocol.*
> *Other GPs could do repeats as needed.*[50]

Anonymous Submission – 4

> *There is no sensible reason why ADHD medication should only be prescribed by a psychiatrist. It is of course appropriate to require a diagnosis by a psychiatrist but, once a patient has been properly diagnosed, the sensible approach is for the GP to have responsibility for repeat prescriptions.*[51]

Anonymous Submission - 7

> *I definitely believe that that this should be expanded to the GPs. The needs of each individual should be carefully discussed. However following titration of medication – monitoring and review by the physiatrist, once stability is achieved then arrangements should be made to discuss the need for ongoing medication and management and the consideration of a shared care agreement with GP. This would have a positive and noticeable impact in reducing the waiting list for assessment and diagnosis for those waiting on the public list.*[52]

Anonymous Submission – 6

> *With my other medications, I have been able to transition to my GP prescribing them relatively painlessly. Why is this not an option for ADHD medication?*
>
> - *I understand that a GP should not be able to diagnose ADHD or prescribe these drugs off their own back, as I know they are stimulants and controlled drugs*
> - *I have no issue with the above*
> - *However, under the supervision of a Psychiatrist & ADHD expert, I believe that putting Methylphenidate on the GP list would be a net benefit to the island as a whole, as well as a benefit to those who need this medication to function*
> - *This approach has been validated in other jurisdictions*[53]

Anonymous Submission – 8

> *GPs should defiantly [sic] be able to prescribe it to make it easier to collect and it will take the strain off of the hospital pharmacy and it will make it more accessible for people who struggle to get into town.* [54]

[50] Written Submission – Anonymous 3
[51] Written Submission – Anonymous 4
[52] Written Submission – Anonymous 7
[53] Written Submission – Anonymous 6
[54] Written Submission - Anonymous 8

Anonymous Submission – 11

> *I believe that once you are diagnosed and stable on a medication dosage, you should move to shared care with a GP and that medication should be free. It would be much more beneficial if I could access more than 1 months at a time too.* [55]

Note – at the time of finalising this report, the Panel received the following submission from the Primary Care Board (PCB):

"*At the recent PCB AGM, members were asked whether they feel it appropriate to take on the prescribing of medication for patients with ADHD and the 'unanimous' majority rejected the idea of shared care prescribing at present. The use of secondary care non-medical prescribers and the option of contracting a community pharmacy to dispense medication could improve access to treatment*"

The Panel notes that this position differs from submissions received from individual GPs, and reinforces the Panel's assertion that the Minister for Health and Social Services should actively engage with the PCB to establish an effective working relationship going forward.

FINDING 17

The Panel understands that a Shared Care Pathway is in discussion with both the Minister for Health and Social Services and the Minister for Social Security. The discussions involve the Shared Care Pathway allowing a referral to be made by a GP and moved onto secondary care for diagnosis and treatment, following which it would be moved back to the GP for ongoing monitoring. Until the Shared Care Pathway protocols are agreed, it is difficult to see how primary care will form part of the overall management of patients with ADHD.

FINDING 18

The Panel understands that some GPs from small practices are reluctant to sign up to the Shared Care Pathway due to the responsibility of prescribing ADHD medication on a day-to-day basis and not having the flow of patients to gain the experience required.

FINDING 19

Following the written submissions from members of the public, the Panel learned that to have GPs prescribe repeat medication would be of benefit and may ease the existing pressure on the one psychiatrist.

FINDING 20

The Department of Health and Community Services is currently discussing with GPs the possibility of them undertaking special interest sessions in some services – one being ADHD. If a GP was particularly interested in an area and wanted to develop some expertise, the GP could work in that area and receive supervision from the specialist which would increase capacity and help with the service.

RECOMMENDATION 6

The Minister for Health and Social Services, together with the Minister for Social Security should continue its discussions with the Primary Care Board to find a solution to additional

[55] Written Submission – Anonymous 11

medical professionals being authorised to prescribe medication. Should this not come to fruition, both Ministers should implement an alternative plan to offer training to existing medical professionals to qualify for prescribing.

The Panel was made aware of another solution that may help alleviate the current pressure on the waiting list which involved GPs undertaking special interest sessions in some services, one of them being ADHD.

Director of Mental Health and Adult Social Care:

> *One of the other things that we have been talking about recently with primary care is GPs undertaking special interest sessions in some of our services and this is one of them. If we have a GP who is particularly interested in this area and wants to develop some expertise, receive supervision from the specialist but also increase capacity and help with the service, that would make really good sense.*

The Panel was informed that this process worked well within the Alcohol and Drug Service where there is a history of a GP working in that sector for a couple of sessions and not just prescribing for people with alcohol and drug-related issues, but prescribing physical health checks.

Deputy L.M.C. Doublet:

> *What would that look like to the patients? What would the costs be? Would it be the same as a GP consultation?*

Director of Mental Health and Adult Social Care:

> *That is the thing we would have to work out. In the past where we have used GP sessions in some of our services, that has been an H.C.S. service, so it just happens to be a GP that is receiving it. I guess one of the things that we are really keen to do is to make it as simple and as seamless for people that use the services. We do not want people to have to pick, I do not want to go there because I would have to pay that there; we want to make it as easy as we can.*

Deputy L.M.C. Doublet:

> *The Health Department pay the GP for their time.*

Director of Mental Health and Adult Social Care:

> *Yes, that is exactly right, yes.*

Deputy L.M.C. Doublet:

> *Okay, so that is a model that is being considered and you think could work.*

Director of Mental Health and Adult Social Care:

> *Yes, yes.*[56]

RECOMMENDATION 7

The Minister for Health and Social Services should explore the option of funding GPs to undertake special interest sessions in ADHD, where they would receive training and supervision from the ADHD specialist, helping to increase capacity and alleviate pressure on

[56] Public Hearing with the Minister for Health and Social Services – 16th October 2024

the waiting list for assessment/diagnosis. This should be carried out by Q2 2025 with an update provided to the Panel of its progress within 3 months of the presentation of this report.

Shared Care Pathways in other Jurisdictions

As discussed in this report, it is hoped the implementation of a Shared Care Pathway would ease the current burden on how ADHD conditions are diagnosed and how medication is prescribed.

NHS England use Shared Care Pathways, particularly in the context of managing long-term conditions, mental health, and cancer care.

Examples of Shared Care Pathways in the UK:

Mental Health Care:

- For individuals with mental health conditions, such as depression or schizophrenia, Shared Care Pathways might involve a GP managing medication and providing initial psychological support, with a psychiatrist providing specialist care. Community mental health teams (CMHTs) or mental health nurses could provide regular follow-up care. The pathway ensures a seamless transition between primary care and specialist services, with clear communication among all involved parties.

Chronic Conditions (e.g., Diabetes, Heart Disease):

- For patients with chronic conditions like diabetes or heart failure, a Shared Care Pathway might involve a GP managing routine monitoring, prescribing medication, and providing lifestyle advice, while a hospital specialist or cardiologist might manage more complex treatment needs. The pathway would also involve regular reviews to monitor for complications and adjust treatment as necessary.

Cancer Care:

- In cancer care, the pathway might include coordinated care between a GP, an oncologist, and hospital staff. After initial diagnosis and treatment in secondary care, the patient may transition back to primary care for follow-up monitoring, with the oncologist offering input as needed for advanced treatments or palliative care.

Palliative Care:

- For patients in need of palliative or end-of-life care, a Shared Care Pathway might involve a GP working alongside palliative care specialists, community nurses, and social workers to ensure that the patient's physical, emotional, and spiritual needs are addressed as they approach the end of life.

Benefits of Shared Care Pathways in the UK:

Improved Continuity of Care:

- A clear plan of action helps to prevent gaps in care, particularly when patients move between different services or healthcare providers.

Better Health Outcomes:

- By coordinating care among multiple healthcare providers, Shared Care Pathways aim to improve patient outcomes, particularly for those with chronic conditions or complex health needs.

Increased Patient Satisfaction:

- Patients feel more supported and involved in their care, as they are part of the decision-making process and experience fewer disruptions in care.

Efficiency and Cost Savings:

- By reducing duplication of services and ensuring that the right care is delivered at the right time, Shared Care Pathways can lead to more efficient use of resources in the NHS.[57]

The Panel is of the opinion that a Shared Care Pathway would be a positive step forward in helping ease the existing burden for repeat prescriptions of medication for ADHD. The following quote is from the Public Hearing with the Minister for Health and Social Services whose Officer touches on the key to a successful Shared Care Pathway.

Director of Mental Health, Social Care, and Community Services:

> *It is a system that works well elsewhere and it alleviates pressure, the prescribing pressure particularly, on the specialists. Shared care is always initiated in secondary care, so it always starts with the specialists, you hand over at the point at which the person is adequately settled for the GP to take on prescribing. But of course GPs have to be able to get specialist advice when they need it under those circumstances. GPs are not specialists in ADHD, so you do not want the GP to be left feeling: "I am prescribing something that I do not feel confident in and I cannot get special advice." So the key to the shared care protocols is making sure that specialist advice is available when it is needed.*[58]

FINDING 21

Shared Care Pathways are used successfully in Jersey, however, do not cover mental health issues. In the UK, they successfully cover areas such as mental health, cancer and chronic conditions such as diabetes. The benefits of Shared Care Pathways include patient satisfaction, efficiency and cost savings and better health outcomes.

Ministerial roles regarding the Shared Care Pathway

During the course of this review, the Panel spoke to both the Minister for Health and Social Services and the Minister for Social Security. For clarification, the Panel asked for the role of each Minister to understand how both would work within the Shared Care Pathway. The Panel was informed that the Minister for Health and Social Services holds the performers list[59]

[57] NHS England » Shared Care Protocols
[58] Public Hearing with the Minister for Health and Social Services – 16th October 2024

[59] The performers list refers to a list of doctors who are approved to act as doctors (perform) in Jersey.

(Prescribed List of Medication) and the Minister for Health and Social Services is responsible for the Medicines Law.

The Panel, during its hearing with the Minister for Social Security asked how one unified health policy could work, and if one Minister would have full responsibility. It was informed that the structure and basics would need to be right first then it would be reviewed for political oversight. The Minister went on to inform the Panel that one Minister with sole responsibility was not something that she would object to.

Associate Director - Public Policy:

The Minister for Health and Social Services holds the performers list and the Minister for Health and Social Services is responsible with Medicines Law. So you are talking about people who are allowed to be doctors in Jersey, that is the Minister for Health and Social Services, and drugs that are allowed to be prescribed in Jersey, and that is the Minister for Health and Social Services as well. So the Minister for Social Security has a kind of subset of those things, if you like.

Deputy L.M.C. Doublet:

It is this diffusion of responsibility again. What is the solution to this?

The Minister for Social Security:

I am actively obviously working with the Minister for Health and Social Services to look at how we can unify the Health Service across primary and secondary care. We do need a service that is able to work proactively all together. I am happy to work as a Minister with the Minister for Health and Social Services and I am not somebody that would be putting blockers in the way of us improving services and making them more efficient into the future.

Deputy P.M. Bailhache:

That is not really answering the question, if I may say so. The question was, what is your solution?

The Minister for Social Security:

I think we do need a single unified Health Service. I am supportive of the proposals that the Minister for Health and Social Services is bringing forward.

Deputy L.M.C. Doublet:

Would that entail a single Minister?

The Minister for Social Security:

A single Minister is not something that I would be opposed to.

Deputy L.M.C. Doublet:

Is that part of the plan?

The Minister for Social Security:

It may well be, I think that at that point we get into the politics of things. I think what we need to get right first is the structure and the basics and then we will look at how

> *that then flows up for political oversight as part of that. That is probably outside the remit of this hearing.*[60]

FINDING 22

The Minister for Health and Social Services and the Minister for Social Security hold different roles with regards to the health service. It is uncertain which Minister would have responsibility for the Shared Care Pathway, or if the role would be shared.

FINDING 23

The Minister for Social Security informed the Panel that one Minister with sole responsibility for the Shared Care Pathway is not something that she would be opposed to.

RECOMMENDATION 8

The Minister for Health and Social Services, together with the Minister for Social Security should discuss roles and responsibilities with a view to one Minister (or Assistant Minister) having sole responsibility for the Shared Care Pathway. These discussions should take place in line with the timeline for the implementation of the Shared Care Pathway with an update provided to the Panel within 3 months of presentation of this report.

[60] Public Hearing with the Minister for Social Security – 14th October 2024

Conclusion

The Panel concludes that there is not enough being done in the Island to address the concerns of those suffering with ADHD. Numerous written submissions from the public mentioned the same issues and people felt generally let down by the current system, noting obstacles in place for the basics, like obtaining medication, adding a burden to an already stressful situation. The Panel found that key issues that needed immediate attention were tackling the long waiting list, additional resource for the issuance of prescriptions, raising awareness of the condition and the inclusion of ADHD medication on the Prescribed List of Medication, making it eligible for subsidy from the Health Insurance Fund (HIF). The Panel also heard that these obstacles were having an impact on their general wellbeing and in addition, communication from the Health and Community Services to those whilst on the waiting list was less than adequate. The Panel believes that addressing these key areas would alleviate the pressure on the current system and as a result, has made a number of key recommendations to ensure that these are tackled as soon as possible. The Panel firmly believes that implementation of these key recommendations could help improve people's lives dramatically and the overall perception of how ADHD is perceived in the Island.

ADHD diagnosis has increased dramatically during the last 2 to 3 years and the Panel would like to see more awareness raised around the condition. It heard from a number of non-Government organisations where work was constantly being done to raise awareness and zones were provided for those with ADHD to gather and share information. The Panel would like to see something similar being brought forward by Government, which could link into possible clinics and hubs being set up with trained staff to issue prescriptions and to offer advice.

The Panel is very much aware of the global shortage of medication which contributes to these obstacles for those with ADHD and hopes this will ease by the end of the year, allowing people more security in obtaining medication and repeat prescriptions being filled accordingly. This would also be a great improvement towards assisting those with ADHD and their overall wellbeing. It does however note that this is a global problem and not one that can be addressed by Government in Jersey.

Although a number of additional issues came to light regarding the challenges faced by those suffering with ADHD, these issues were outside of the Panel's Terms of Reference. The Panel would have liked to tackle all issues raised however, due to the scope of its report, was unable, however will monitor these areas during its public hearings with the relevant Ministers.

Appendix 1

Panel membership

The Panel comprised of the following States Members:

Deputy Louise Doublet (Chair)

Deputy Jonathan Renouf (Vice-Chair)

Deputy Philip Bailhache

Deputy Lucy Stephenson

Terms of Reference

Health and Social Security Panel

Review of Prescription of Medication for ADHD

Terms of Reference

1. To evaluate the current procedures and frequency for prescribing ADHD (Attention Deficit Hyperactivity Disorder) medication

2. To identify any obstacles in the prescribing of ADHD medication

3. To assess the impact of any obstacles on patient wellbeing and overall health

4. To evaluate any shortage of ADHD medication and review how this could be mitigated, if at all

Evidence considered

Responses to written questions were received from the following Ministers:

• The Minister for Health and Social Services; and

• The Minister for Social Security

The Panel also held Public Hearings with both Ministers.

There was a public call for evidence and requests for written submissions were sent to 15 stakeholders and responses were received from the following:

- ADHD Jersey
- AmNeurodiverse
- CAMHS
- Primary Care Body
- Autism Jersey

It should be noted that the Panel received a number of submissions from private practitioners who wished to remain anonymous or confidential. To view all the submissions, responses to written questions and Public Hearing transcripts, please visit the review page on the States Assembly website.

Review Costs

Public Hearing Transcripts

£150 (per audio hour) x 6 hours = £900

Digital and Public Engagement

A D&PE plan will be prepared for the Panel's consideration although it is envisaged that the type and scope of this particular review will not require any additional budget for advertising / call for evidence etc. a minimal budget is included at this stage to promote the Panel's review with paid sponsored social media posts = £90

Total = £990

What is Scrutiny?

Scrutiny panels and the Public Accounts Committee (PAC) work on behalf of the States Assembly (Jersey's parliament). Parliamentary Scrutiny examines and investigates the work of the Government, holding ministers to account for their decisions and actions. They do this by reviewing and publishing reports on a number of areas:

- Government policy;
- new laws and changes to existing laws;
- work and expenditure of the Government;
- issues of public importance.

This helps improve government policies, legislation and public services. If changes are suggested, Scrutiny helps to make sure that the changes are fit for purpose and justified.

The Health and Social Security Scrutiny Panel reviews policy and legislation related to the topics of Public Health and Social Care. The Panel reviews topics under the remit of the Ministers for Health and Social Services and Social Security and considers and scrutinises draft legislation, policies and other matters of public importance. To learn more about the Panel's work please click here.

Appendix 2

Social Prescribing and Alternative Support Services

Social prescribing is an approach that connects people to activities, groups, and services in their community to meet the practical, social and emotional needs that affect their health and wellbeing. It is an increasingly widespread practice in health services around the world and has been proven an effective method of preventative healthcare, particularly for mental health improvement. It is appropriate for all ages and works particularly well for people who:

- have one or more long term conditions
- who need support with low level mental health issues
- who are lonely or isolated
- who have complex social needs which affect their wellbeing.

Accurate data does not currently exist, but it is estimated that approximately 20% of patients who consult their GP do so for primarily social issues, given this and the driving forces of an increase in those waiting for a mental health diagnosis and growing demand on services, social prescribing is gaining popularity.

Earlier this year the Elemental Social Prescribing Platform was launched for Jersey. All GPs should be trained and accessing the social prescribing system by the end of 2025.

During its hearings with the Minister for Social Security and the Minister for Health and Social Services, the Panel discussed the use of social prescribing to support those with ADHD and those awaiting diagnosis;

Deputy L.M.C. Doublet:

.... *I am going to ask about social prescribing because many of our submissions have noted that they would prefer a non-pharmacological prescribing, so rather than medication they would like to have access to perhaps support groups or talking therapies or online courses and some of the charities that are established already spoke to us about how they are providing some of those, and some of it is funded, some of it is not currently funded. We are also aware of the Connect Me social prescribing project, thank you for providing a briefing on that, it was very interesting. On the Connect Me first of all, there is a budget of £325,000 being proposed. Is that funding adequate for the Connect Me generally and will it assist people with ADHD to access some of these social solutions that they are asking for?*

The Minister for Social Security:

Firstly, I would hope that it will enable people with ADHD to access some of those solutions. I have been impressed by what I have seen. I think I have had a very similar briefing to what was given to the panel just last week. It has not been suggested to me that there is a funding pressure, but of course this is a new pathway as well. Everything seems positive so far and I look forward to getting the first reports on some outcomes from the Connect Me programme

with the social prescribing. But it is very new, literally just launched, and I think a really positive thing.[61]

Deputy L.M.C. Doublet:

We spoke about social prescribing quite a bit in the previous hearing with the Minister for Social Security, so this leads nicely into that. We are aware that there is a scheme that Government have launched. It is something that those who have made submissions to us and also people who have come in and spoken to us about their experiences, have spoken quite passionately about having alternative options, for alternatives to medication in terms of treating their ADHD. What kind of relationship do you have with charities? Are there any funded charities or commissioned services that are providing things like this outside of the health service?

Director of Mental Health, Social Care, and Community Services:

We are clearly really tied into the social prescribing projects; that is across a whole raft of our services, including this one. That is something that we are actively supporting and involved in. The steering group that is developing the strategy has charity representation on it. One of the things that I have no doubt the strategy will do will be indicating where there are more things that can be done but do not need to be done by H.C.S., can be done by other partners. I anticipate that is something that will fall out of the strategy.[62]

Government of Jersey Social prescribing intervention - Connect Me: connecting our communities grant scheme

Launched in 2020, the Connect Me initiative is a network of Jersey based charities, community groups, health professionals, and volunteers offering community-based activities and services. Inspired by the practice of social prescribing as a form of preventative healthcare, the initiative aims to enhance mental health and combat loneliness through social engagement. It promotes social mobility and inclusion as a non-medical alternative for improving well-being.

Grants of up to £5,000 are available for projects which will increase opportunities for Islanders to participate in artistic or physical activities. To date, 95 organisations have received Connect Me grants and an estimated 25,000 Islanders have benefited from the 150 projects funded by the Connect Me scheme.

Alternatives to medication

During its hearing with the Minister for Health and Social Services, the Panel discussed ADHD referrals and the planned implementation of a programme of psychological support and interventions for people on the waiting list, due to be in place by the end of November 2024.

[61] Public Hearing with the Minister for Social Security – 14th October 2024
[62] Public Hearing with the Minister for Health and Social Services – 16th October 2024

Director of Mental Health, Social Care, and Community Services:

We are due to run the first of the groups in the first week of November. This is a response to feedback that we have had from people who use the service and people that are waiting. The focus is primarily always on medication. There are lots of other things that we can be doing to help people with ADHD. There are lots of things that we could be doing to help people with ADHD while they are on the waiting list and some of that is about psychological management of the condition. We have developed through our psychological service and mental health services a Living with Neurodiversity group and that group is going to be up and running from November. We are hoping to run it twice a month. Clearly, we are not going to get everybody seen quickly but I am hoping that this will be an intervention that will help signpost people to other places but also provide people with some skills and support while they are waiting to be seen.[63]

Charities, Support Groups and Advocacy Organisations

The Panel contacted relevant charitable organisations during the course of its review. The two main organisations in the Island that offer support and advocacy for those with ADHD are:

AllMatters Neurodiverse Jersey
A charity dedicated to promoting understanding and acceptance of neurodiversity. Their mission is to spread awareness and provide support to individuals who are neurodivergent, including autism, ADHD, dyslexia, and any other neurological differences.

ADHD Jersey
Is a peer-led non-profit organisation. Their mission is to raise awareness about ADHD and provide support to individuals in the community affected by this condition. They have a team of volunteers, all with personal experience of ADHD, who offer resources, guidance, and a sense of community to those in need. Through educational initiatives, advocacy efforts, and empowerment programmes, they aim to uplift and empower individuals with ADHD to reach their full potential.

Neuroinclusive strategy for Jersey

In 2024 the Minister for Health and Social Services has committed to creating a 3-year Neuroinclusive strategy for Jersey in partnership with Autism Jersey and other relevant charities.

Neurodiversity is a term which covers a range of neurological or developmental conditions including:

- Autism
- ADHD
- Dyslexia
- Dyspraxia
- Tourette's syndrome

[63] Public Hearing with the Minister for Health and Social Services – 16th October 2024

Neurodiversity can create challenges with communication, thinking, language and changes to personality.

The strategy will identify how Government can better support neurodivergent individuals within the community and provide them with improved support services and raise awareness.

Input has been sought to inform the strategy from neurodivergent individuals, friends, relatives and supporters of neurodivergent people and neurodiversity advocates.

Reasonable Adjustment Policies in the Workplace

Employers make reasonable adjustments to make sure workers with disabilities, or physical or mental health conditions, are not substantially disadvantaged when doing their jobs. The aim being to foster a culture of inclusivity and maximise the potential of employees.

Reasonable adjustments refer to changes an employer can make to reduce the disadvantages faced by an employee or candidate with a disability. Employers in Jersey are legally required to make reasonable adjustments when requested by an employee under the Mental Health (Jersey) Law 2016.

ADHD Jersey advocates for ways that employers can become more inclusive to neurodiverse staff and offers training courses to support with this. Their sessions are designed to educate employers and employees on various topics related to ADHD, while also encouraging conversations, increasing awareness and reducing stigma.

The charity offers companies practical strategies for supporting neurodiversity while helping employees manage their responsibilities. They aim to provide insights on how an employer can embrace neurodiversity and foster a more inclusive environment by understanding the benefits of accommodating neurodiverse individuals, leading to improved productivity and enhanced business performance.

Reasonable adjustments take on many forms depending on an individual's needs, they could include providing accommodations such as:

- quieter spaces,
- noise-cancelling headphones
- flexible working arrangements
- reasonable modifications to the physical workplace such as removing bright lights
- changes in how tasks are carried out
- providing additional assistance
- written instructions given to someone with memory problems.
- altering shift patterns or break frequency.

Raising awareness

October has been designated as ADHD awareness month. The goal of the UK based campaign is to provide reliable information and resources to help people thrive with ADHD. The theme for 2024 was 'Awareness is Key'.

The awareness month and a recent conference on ADHD, organised by the Health and Community Services Education Department, was discussed during the hearing with the Minister for Health and Social Services.

The Minister for Health and Social Services:

We were just discussing this a little bit earlier and what you will have seen is there has been a limited approach to it simply because I think that our common view is that we really need to get things resolved before we raise too much more awareness of the condition. I am hoping that by this time next year we are able to make more of it by virtue of the fact that we have made some advances in some of the problems that I am sure we are going to discuss during the course of the next hour and a half.[64]

The Panel learned that Health and Community Services sponsored a conference on ADHD which had key speakers from both on and off the Island.

Director of Mental Health, Social Care, and Community Services:

So it was a conference that was set up by the Education Department within HCS (Health and Community Services) and it was really successful, the feedback has been excellent. We had a range of speakers, we had speakers from on Island and people from off Island that are considered to be expert in this area. We had a presentation from one of the charities here, for example. So it was primarily aimed at raising awareness among professionals, so that was the primary aim of the conference. But it was not just professionals that attended and, from all of the feedback that we have had to date, people found it very useful. There was a lot of discussion, people felt able to engage and perhaps even create some new networks which will help with that awareness raising.

The Panel went on to ask if awareness of ADHD was promoted as much as it should be.

The Minister for Health and Social Services:

Perhaps not to the extent that it should be, because it is an evolving situation, is it not? When I was a child, ADHD had never been heard of and I think it is now coming to public attention. There are more people realising that they have the condition, and I think there is a growing awareness of it and it is something that is going to take time for it to be fully understood by everybody. As I say, there is this dilemma at the moment of making sure that we get the treatment right before we make too much noise about the awareness of it. So it is a fine balance that we are dealing with at the moment.

FINDING 24

Awareness of ADHD is not as prominent as it should be. The Panel was informed that this was due to it being an evolving situation and areas needed to be resolved prior to undertaking raising awareness.

[64] Public Hearing with the Minister for Health and Social Services – 16th October 2024

RECOMMENDATION 9

The Minister for Health and Social Services together with the Minister for Social Security must consider a programme of activity to support ADHD Awareness Month 2025. This should be carried out within ample time for preparation for the next ADHD awareness month.

The Journey from Assessment to Diagnosis

Patients are usually referred to the ADHD specialist from their GP (or other health specialists from primary care). There is also an option for self-referral into the mental health services via Jersey Talking Therapies (JTT).

The Panel learned that those who self-refer are sent a screening tool for completion which provides additional clinical information. This then allows the self-referral to be assessed and correctly placed on the waiting list, or referred to another area, if necessary.

Deputy L.M.C. Doublet:

The screening tool, at what stage in the pathway is that used?

Director of Mental Health, Social Care, and Community Services:

Right at the beginning.

Deputy L.M.C. Doublet:

By the GPs?

Director of Mental Health, Social Care, and Community Services:

No, it goes to the person, the referral. You can self-refer into our services, you do not have to be referred by a GP So what we are now doing is, when people are initially referred, we are sending them a screening tool for completion and that means there is more clinical information available, it helps us potentially sift out people who may not correctly be placed on the waiting list, but also it means that, when we come to do the assessment, we have got a lot of clinical information available to us already.[65]

Jersey Talking Therapies (JTT)

Jersey Talking Therapies is part of the Government of Jersey Health and Community Services Department. We offer free and confidential psychological therapy for resident adults aged 18 and above living in Jersey. [66]

This service is for people who experience:

- low mood
- depression
- anxiety, worry, stress and feelings of panic
- obsessive compulsive disorder (OCD)
- specific fears, also known as phobias
- intrusive and unwanted thoughts

[65] Public Hearing with the Minister for Health and Social Services – 16th October 2024
[66] Jersey Talking Therapies (JTT)

- post-traumatic stress disorder (PSTD)
- traumatic events
- patterns of disordered eating
- social anxiety
- mild-moderate alcohol use difficulties

Additional Support

Medication for treatment is available in Jersey however as discussed in this report, the waiting list for diagnosis is 3.5 years.

The Panel was informed by the Minister for Health and Social Services, in a letter dated 3rd September, that there was a planned implementation of a programme of psychological support interventions for people on the waiting list (this will be in place by the end of November). The Panel asked for further information on this at its Public Hearing on 16th October. It was informed that the first of the groups was due to run in the first week of November. It was explained to the Panel that the focus was generally on medication to alleviate ADHD symptoms however, there were additional treatments that could be offered to those on the waiting list. It was further explained that each would likely be between 10 and 12 people and led by an Assistant Psychologist who would be supervised.

Deputy L.M.C. Doublet:

What format does that group take?

Director of Mental Health and Adult Social Care:

It is a group of between 10 and 12 people. It is led by an Assistant Psychologist who is supervised. It is a closed group, so it is a group that people will come to. I think it is 2 sessions I think but it may be 3. People are given information but also have the opportunity to talk about their own experiences, how that relates to them and given some tools around managing some of the presentation.

It was hoped the groups would run twice a month however, the Panel raised concern that with the long waiting list and each group accommodating 10 to 12 people, it could take quite a while for everyone on the list to gain access. The Panel asked if there was potential for expanding staff to enable more people to access the group. It was informed that it wasn't specifically a staffing issue, more that the implementation of the group was new and it would be some time to understand its success and the areas in which it needed to be improved.

Deputy L.M.C. Doublet:

Okay. It will be quite a while before everybody on the waiting list can access it. Is there potential for you to expand the staffing of that to enable more people to access it?

Director of Mental Health and Adult Social Care:

It is not really a staffing issue. We are running a number of psychological groups in this way that are new and this is one of a package. But, potentially, we will have a look at what the uptake is like and we might have to team local our resource but it may be that there is some stuff that we do more of and some stuff that we do less of. Yes, we will see how we go.

Appendix 3

Statistics in Jersey over last 5-10 years

The Minister, in his letter to the Panel of 3rd September informed it of the numbers of those waiting to receive a diagnosis.

> *As at the end of August, the number of adults on the ADHD assessment waiting list is 778. This number has reduced from 817 in June because of the work that is being undertaken on the waiting list. The number of children & young people waiting to transition into adult services remains the same.*

The Panel learned that 40 referrals were still being made each week which had gone up slightly in the last 2 months.

Deputy L.M.C. Doublet:

> *Could you advise us what the current numbers are on the waiting list?*

Director of Mental Health, Social Care, and Community Services:

> *So the current waiting list for adults as at today is 873 people waiting for an assessment.*

Director of Mental Health, Social Care, and Community Services:

> *So we are still receiving an average of 40 referrals a month. That has gone up slightly in the last 2 months*

This led into the Director of Mental Health, Social Care and Community Services informing the Panel that any referrals made 'today' (being the date of the hearing on 16th October), the current wait time would be 3 and a half years. However, it was informed that in the United Kingdom the longest waiting list was in the UK which was 10 years.

This is in contrast to a statement from the Director of Adult Mental Health and Adult Social Care to ITV Channel Islands on 16th March 2023 that

> *Adults in Jersey are waiting more than 10 months for an Attention Deficit Hyperactivity Disorder (ADHD) assessment.*
>
> *Statistics from the end of February 2023 show that 396 adults are currently waiting an average of 306 days to get a diagnosis.*

This is an increase of 382 people in 17 months.

Statistics in the UK – 2019 to 2024

Waiting Times

There is no national data published on referrals or waiting times for ADHD assessments, which means that the challenges can go unrecognised. The Petitions Committee in the UK ran an online survey asking people their views on assessment waiting times for ADHD and autism, which was debated by MPs in February 2023. The survey found that, of the respondents who were waiting for an NHS ADHD assessment, 24% had been waiting between one and two years and 10% had been waiting between two and 3 years. Meanwhile, the rise in demand for ADHD support can be seen through the lens of national prescribing data. Between 2019/20 and 2022/23, there was a 51% increase in the number of patients prescribed medication for ADHD.[67]

The NHS

The Autism Waiting Time Statistics provided on the NHS website is a series of publications documenting the experience of waiting times within autistic spectrum disorder (ASD) diagnostic pathways. These are experimental statistics and are published to involve users and stakeholders in their development to build in quality and reliability at an early stage. As such, they remain under constant review, although major changes to methodologies are made between reporting years in order to preserve time-series. An overview of these can be found below with more detailed reporting found by following this link.

For adults the variation is equally stark – it varies from 12 weeks at Dorset Healthcare University NHS Foundation Trust to 550 weeks (over 10 years) at the Herefordshire and Worcestershire Health and Care Trust.

The adult waiting the longest has been waiting 443 weeks (8.5 years). There are in Wales at the Hywel Dda University Health Board.

Referral Waiting Times

In March 2024, there were 183,733 patients with an open referral for suspected autism. Of these, 160,396 (87.3%) had a referral that had been open at least 13 weeks.

First Appointments

In March 2024, 5.6% (9,034) of the patients with an open referral that had been open more than 13 weeks had had a first appointment within the recommended 13 weeks.

Open/Closed Referrals

There were 9,377 new referrals and 7,858 closed referrals in March 2024. This is a decrease of 34.6% for new referrals and an increase of 0.5% for closed referrals compared to March 2023.

A full guide to the latest statistics and graphs provided by the NHS can be found here.

[67] https://www.nuffieldtrust.org.uk/news-item/the-rapidly-growing-waiting-lists-for-autism-and-adhd-assessments

States Greffe | Morier House | Halkett Place |St Helier | Jersey | JE1 1DD
T: +44 (0) 1534 441 020 | E: statesgreffe@gov.je | W: Statesassembly.gov.je