

Oifig an Stiúrthóra Náisiúnta um Rochtain agus Imeascadh

Ospideal an Dr.Steevens Baile Atha Cliath, D08 W2A8 Office of the National Director Access and Integration

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Deputy Rose Conway-Walsh Dáil Éireann Leinster House Dublin 2 13th February 2025

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PQ 1628/25 - To ask the Minister for Health to outline the appropriate pathway to secure a diagnosis of autism and ADHD in adults; and if he will make a statement on the matter. -Rose Conway-Walsh

Dear Deputy Conway-Walsh,

The Health Service Executive has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted to the Minister for Health for response.

HSE Access and Integration contacted colleagues in both the Mental Health and Disability Services Care Groups for a response to your question.

Responses from Bernard O'Regan AND Disability Services and Dr Amir Niazi National Clinical Advisor & Group Lead for Mental Health Clinical Design and Innovation are included.

I trust this is of assistance to you.

David Walsh National Director Access and Integration

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Appendix 1 - Response from HSE Disability Service

PQ: 1628/25- To ask the Minister for Health to outline the appropriate pathway to secure a diagnosis of autism and adhd in adults; and if he will make a statement on the matter.

Disability services are provided based on the presenting needs of an individual rather than by the diagnosis of the individual or the type of disability. Services are provided following individual assessment according to the person's own individual service and support needs.

For adults who may be autistic, a GP may refer to adult psychology in Primary Care or a Multidisciplinary Adult Disability Team.

It is acknowledged however, that the current system is very variable across the country and does not adequately serve the needs of autistic adults. In many areas, adult assessments are only available privately; this is an unsatisfactory situation and we are working to address this.

Service Improvement Programme

The Service Improvement Programme Board for the Autistic Community has been tasked with leading out on an agreed set of priorities that will have greatest impact in terms of shaping how services can be delivered to autistic people. It is also tasked with creating greater awareness of autism in terms of supporting clinicians, other staff and local communities in promoting inclusion and fostering positive attitudes.

The Assessment and Pathways Working Group was established to develop a standardised assessment approach for use in all services dealing with the assessment of Autism to ensure that every assessment is of an acceptable and agreed standard, regardless of which service is being accessed. In addition, it seeks to agree a standardised service user journey and the implementation of a consistent core service offering across those providing services to people who are Autistic.

The Working Group, including people with lived experience of autism, has consulted widely with key stakeholders in the design and formulation stage of the project; which has been particularly important in the context of the implementation of a tiered approach to assessment.

Its main work focus is:

- To develop an operational model for a tiered approach to Autism Assessment through developing clear and functioning pathways to services.
- To strengthen Disability, Primary Care and Mental Health services by operating a shared Model of Service.
- An implementation plan to include training which takes cognisance of existing policies of the HSE.

The 2nd and final Phase of the Protocol piloting is now complete, as is its independent evaluation undertaken by the Centre for Effective services.

Following incorporation of learnings from the evaluation and further consultation workshops with professional bodies and civil society, we anticipate that national rollout of the final version of the protocol will commence with training in each of the 6 Health Regions before the end of Q1 2025.

The Protocol with be reviewed annually and any new learnings will be incorporated as required.



Oifig an Chomhairleora Chliniciúil Náisiúnta agus Ceannaire Grúpa do Mheabhairshláinte

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Appendix 2 - Response from Mental Health

PQ 1628/25: To ask the Minister for Health to outline the appropriate pathway to secure a diagnosis of autism and adhd in adults; and if he will make a statement on the matter. -Rose Conway-Walsh

ADHD in Adults National Clinical Programme

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterised by inattention, hyperactivity and impulsivity (American Psychiatric Association, 2013). Once viewed as a childhood disorder, it is now widely accepted that ADHD persists into adulthood in a proportion of individuals, resulting in some people in functional impairments such as higher rates of academic failure, impaired social functioning, difficulty with emotional regulation and increased substance misuse (Willcutt et al., 2012; Lee et al., 2016; Beheshti et al., 2020, Groenman et al., 2017; Sundquist et al., 2015). Recent research estimates that adult ADHD has a prevalence rate of 3.4% -4.4% (Faroane 2005, Kessler 2006) with 3% having the full syndrome (Ayano 2023).

An adult who has just received a diagnosis of ADHD is in a very different situation compared to a child with ADHD. The adult has sought the diagnosis so has insight into his/her life being less than satisfactory and, crucially, wishes to change it. Ultimately he/she is hoping for a functional change: psychologically, socially and educationally/occupationally (BAP 2007).

The specific aims of this Clinical Programme are:

- 1. To provide for the assessment of adults with symptoms suggestive of more severe/complex ADHD by trained and skilled staff. With this degree of severity, a person has significant impairment in two or more aspects of their life.
- 2. To provide multi-modal treatment involving a combination of pharmacological and non-pharmacological interventions.
- 3. To ensure that young people attending CAMHS for ADHD who continue to have significant symptoms of ADHD, as outlined earlier, can be transferred to their Adult ADHD Service and that this transfer is planned by CAMHS a year in advance to ensure it occurs smoothly.
- 4. That all of the above is delivered through a clearly defined and integrated clinical pathway.

Up until 2022 the Department of Health (DOH) provided funding to the National Clinical Programme for 3 of the 11 Adult ADHD NCP sites (2.5 teams). These are now operational and cover the following areas:

CHO1: Adult ADHD team for Sligo/Leitrim/Donegal
CHO3: Adult ADHD team for Limerick/Clare/North Tipperary
CHO6: Adult ADHD team covering Dun Laoghaire, Dublin South East and Wicklow
(North, South and East).

Through the HSE's 2022 estimates process the DOH funded 3.5 new teams

CHO4 – Cork: covering North Lee, South Lee and North Cork (ADHD team at
1.0WTE) which opened in March 2023.

CHO4 – Kerry/West Cork (ADHD team at 0.5WTE - smaller population) opened on a
phased basis initially in Kerry but now also covers West Cork. Funding is being
sought for a further half time team as the current service is being overwhelmed by the
referrals arising from the Maskey Report into the South Kerry CAMHs Service.

This was recently granted for the consultant post.
CHO7 - Dublin South City, Dublin South West and Dublin West (ADHD team at
1.0WTE)

□ CHO8 - Midland counties – Laois, Offaly, Longford and Westmeath as well as Kildare West Wicklow (ADHD team at 1.0WTE): Consultant recruited following second international campaign in December 2023 and took up post in April 8th 2024. Funding for 3 of the remaining 4 posts for this team was taken for time related savings in December 2023. Minister Butler in her 2024 announcement on the allocation for funding from the recurrent 10 million euro provided for funding for 2 of these 3 posts (CNS and senior psychologist) and on this basis the Head of Mental Health CHO8 agreed to fund the administrator post.

In **2024** further funding was allocated to develop a team in CHO1 and 8 to provide for: Cavan, Monaghan, Louth, Meath

In Budget 2025 further funding was allocated to develop the remaining catchment area based teams:

- CHO2 including: Mayo, Galway and Roscommon
- CHO5: including: South Tipperary, Carlow, Kilkenny, Waterford, Wexford
- CHO9: including: Dublin North, Dublin North Central, Dublin North West and County Dublin

HSE Recruitment Embargo

This was imposed in November 2023 and it prohibited the filling of all new and vacant posts and has had a very negative impact on the operational services and has delayed the establishment of the one new service.

Table 1: Shows the full Distribution of proposed ADHD clinics Green = operational, Orange = in recruitment and Black = funding allocated 2025

СНО	County	Population 18-64 years	Total Population	Prison	ADHD Clinic Allocation
	Donegal Sligo Leitrim	86,828 38,950 24,501	150,279	-	0.5 Team
1	Cavan Monagha n Louth Meath	43,968 36,245 86,614 108,269	275,096	-	1 Team
2	Mayo Galway/Roscommo n	75,630 197,041	272,671	Р	1 Team
3	Limerick Clare North Tipperary	120,391 70,537 41,869	232,797	Р	1 Team
4	Kerry Cork	88,146 335,010	423,156	Р	1.5 Teams
5	South Tipperary Carlow Kilkenny Waterford Wexford	52,522 43,289 51,147 68,980 88,571	304,509	-	1 Team
6	Dublin South East	286,670	286,670	-	1 Team
7	Dublin West Dublin South City Dublin South West	266,497	266,497	P x 2 ¹	1 Team

7.	+8	Kildare West Wicklow Westmeath Offaly	143,344 53,816 46,245	318,061	Р	1 Team	
		Laois	23,831 50,825				
;	9	Dublin North Dublin North Central Dublin North West	404,063	404,063	P x 3 ¹	1 Team	
		Total	3,007,142				

Model of Care

- 1) Referral for all areas is through the patient's GP to their local Community Adult Mental Health Team. Assessment is carried out by staff trained in ADHD assessment and treatment within The Adult ADHD Services.
- 2) Central to treatment is a discussion with the person on options available and recommended with the person considering:
 - (i) If he/she wishes to commit to treatment
 - (ii) And, if so, which of the options to choose

Following this a jointly agreed individual care plan is drawn up by the ADHD specialist with the person. The ADHD in Adults National Clinical Programme's Model of Care was launched on the 14th January, 2021. When fully implemented, 11 Adult ADHD Clinics will be established to provide assessment and multi-modal treatment in the CHOs in line with the Model of Care. Treatment of adults with ADHD should be multimodal (Kolar 2008; Knouse 2008; Murphy 2005; Weiss 2008) i.e. a combination of pharmacological and psychosocial interventions the purposes of which are to reduce core symptoms of ADHD (inattention, hyperactivity and impulsivity and also mood lability) whilst teaching the individual skills and strategies to overcome functional impairments.

The programme is being evaluated by the UCD School of Psychology with the 3 initial sites taking part in this research.

Waiting lists

HSE Community Operations are developing a data system to capture data in community services at patient level. There is a very limited manual system in place which currently calculates waiting times for each team for this reason.

The only waiting list is data available is shown in the table below and was collated in December 2023.

Phase 2

It is difficult to estimate the unmet need for adults with ADHD as up until 2018 there were no specific public services available. It is now accepted that up to 3% of the adult population have ADHD.

Team Staffing		ng		Clinical	Referra	Referrals	Numb	Estimated
	Admi	Clinic	WTE	Capacit	Is	assesse	er	waiting
	n	al	Appr	У	accepte	d YTD	waitin	time
		WTE	oved		d YTD		g	
CHO1	1	1.	2.5	60%	197	87	336	2 years
Sligo/Leitrim/Doneg		5						
al 1								
CHO6 Dublin SE/	1	3	4	75%	448	143	470	3.5 - 4
Wicklow NS								years
CHO3	1	2	5	40%	123	128	147	1.5 years
Limerick/Clare/ N.								
Tipp								
CHO4 Kerry/West	0.5	1.	2.5	60%	293	184	149	1 year
Cork 1		5						
CHO4 Cork City/	1	3	4	75%	270	124	146	1 year
2								
NE Cork								

However, experience in Ireland and elsewhere indicates there is a very large and significant unmet need. This is for both those with more severe complex ADHD but also for those with mild- moderate ADHD. This includes a significant group of adults who have over the years managed their ADHD by a variety of external supports and/or personal routines. They appear to function well but suffer considerably from symptoms such as anxiety, depression, over-inclusive thinking and mind wandering.

These two groups do benefit from receiving a diagnosis, psycho-education, advice on environmental modifications and in some instances ADHD specific medications. The Programme is now examining how the needs of these people can be met by developing a primary care component which would work in an integrated manner with the services currently being developed and with the Programme's partner, ADHD Ireland.

The operational services have provided invaluable information, common to all.

These are:

- An overwhelming number of referrals far in excess of the estimated number with services already having waiting lists of between 1-4 years.
- These reflect the absolute lack of public service availability in Ireland until the NCP Adult ADHD Services were established.
- This lack also reflects the backlog of people without a service accruing over many years.
- Contributing to this is the absence of any HSE Primary / Disability Care service response to ADHD in adults.
- In addition, the pandemic uncovered ADHD in people who found working at home impossible because of the absence of the usual structures in the office or in 3rd level education which supported them to function, notwithstanding their ADHD.
- Public awareness about ADHD has simultaneously increased during this time reflected in an increased demand for access to ADHD assessment and treatment; this has been noted internationally with several countries reporting a surge in demand for Adult ADHD services.

It was agreed by ADHD Ireland and the National Clinical Advisor for Mental Health (NCAGL) in December 2023 that the NCP will work jointly with ADHD Ireland to develop a document recommending any amendments required within the NCP's model of care and how an integrated stepped / tiered care response to ADHD in adults may be provided. The partnership in this endeavor reflects that the only public services currently available are provided by ADHD Ireland and the HSE Mental Health Services and also underlines the importance of ensuring the opinion of adults with ADHD is a central feature of the document in line with one of the five principles of Sharing the Vision, Government policy on Mental Health Services. It is was agreed that this document will be developed by the Clinical Lead for the NCP and a consultant psychiatrist employed by ADHD Ireland on a part-time fixed term contract specifically for this purpose and this work commenced in February 2024.

Two initiatives have been developed jointly with ADHD Ireland and the UCD School of Psychology. These are:

- An Adult ADHD App now available on the App Store.
 - The Understanding and Managing Adult ADHD Programme (UMAPP). This is a 6 week programme in workshop format delivered through ADHD Ireland by a senior psychologist funded for 2023 by the HSE. Feedback is very positive and Minister Butler allocated re-current annual funding of €142,000 in 2024 to ensure its ongoing availability. By year end 2024, 2305 had completed the course in just over 2 years.

Taken together, Phase 1 and Phase 2 when fully implemented together with the ADHD Ireland initiatives should provide an integrated, stepped care approach to meet the needs of people with ADHD at the level of intervention required by each individual's symptoms. However considerable education of the general public as a whole and specific professional groups such as teachers, university staff, HR managers etc. is essential to ensure the need of people with ADHD can be met in a person centred holistic manner based on supporting their identified needs.