



**PUBLIC PETITION NO.**

**PE01402**

### Name of petitioner

Richard Jones on behalf of Addressing the Balance

### Petition title

A strategy and policy for diagnosing and treating adult ADHD in Scotland

### Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to develop and instigate a strategy and policy for diagnosis and treatment for adult ADHD. For the estimated 60,000 adults with undiagnosed and untreated ADHD in Scotland, the adverse impact on their lives as a result of the condition and the huge and unnecessary costs to society is untenable.

### Action taken to resolve issues of concern before submitting the petition

FOI request submitted to each NHS Board in Scotland, to reply on the actions undertaken in their respective geographic areas and asking eight questions:

1. Who in your organisation is the lead clinician for adult mental health services with responsibility for diagnosis and treatment of adults with ADHD?
2. Has any local service needs assessment been carried out by your NHS board for persons over the age of 18 with ADHD?
3. What arrangements are in place for young people with ADHD as they move into adult mental health services?
4. What services are in place for young people with ADHD who have made the transition to adult services?
5. Are these considered as specialist services specifically for ADHD?
6. Is there explicit mention of services for adults with ADHD (or equivalent term) in your integrated services plan(s)?
7. Are there any other plans, for the development of services for adults with ADHD?
8. Are there agreed timescales for implementation of any ADHD related aspects of these plans and if yes, what are these timescales?

Key to abbreviations used: GAP (General adult psychiatrist), MDT (Multi discipline team), S/W (Social Work), CAMHS (Child and Adolescent Mental Health Services), OT (Occupational Therapist), CMH (Community Mental Health), AMH (Adult Mental Health), CHP (Community Health Partnership).

The two classifications for Attention Deficit Hyperactivity Disorder included in the questionnaire are the Diagnostic and Standards Manual IV (DSM-IV), including the three diagnostic sub-types and the International Classification of Diseases – 10 (ICD-10). ADHD as an abbreviation relates to both classifications.

We have received all of the responses to our FOI requests, and the responses agree with the experiences of adults with ADHD across Scotland coming to us for help, all

show the same picture, that there few provisions for specific diagnostic or clinical pathways for the treatment of adult ADHD in Scotland, leaving those with this often debilitating condition mainly undiagnosed, and therefore untreated.

Key findings from questionnaires:

- Only one NHS Board has completed a needs assessment for adult ADHD.
- Only one NHS Board mentions adult ADHD in their integrated services plans.
- Three NHS Boards are considering development of services for adults with ADHD.
- Eleven NHS Boards have no consideration of developing services for adults with ADHD.
- One NHS Board considers that adult ADHD alone does not meet the criteria for adult mental health services, or only as an exceptional case.

From this we conclude that services are not consistently applied across the country. Children and young people who are diagnosed with ADHD often have their care abruptly stopped once they reach the age of 18, despite medical research that many patients continue to suffer the effects of ADHD throughout their adult lives. Patients with ADHD undiagnosed in childhood have an even more difficult route to appropriate care, they are often unable to obtain a diagnosis as a result of confusion about the condition in primary care or finding that the expertise and knowledge is not available from general psychiatric practitioners.

Confirmed by our FoI requests and by the many patients who travel sometimes long distances to come to the Central Scotland Adult ADHD Support Group, from as far afield as the Highlands and Islands, Ayrshire, Glasgow, Fife, and the Scottish Borders, the only existing clinic for ADHD adults in Scotland is run by NHS Lothian.

Adults with ADHD coming to our charity for help report that GPs are often unfamiliar with the condition, fail to refer for a diagnosis and that general psychiatrists are not trained to diagnose or treat it. There is substantial scepticism about the condition from health professionals who do not have experience of assessing and advising those with ADHD about the condition. This does not give a fair chance to those wanting an objective assessment. We have numerous case examples from our members which demonstrate that primary health care is unfamiliar/unwilling to refer adult ADHD cases to adult mental health services for assessment. We suspect that GPs often lack satisfactory guidance on criteria for making referrals for adults with ADHD.

We believe that with improvements resulting from an integrated clinical pathway for adult ADHD and matching evidence based treatment to clinical demand, improvement in services can be delivered within existing resources leading to better outcomes and savings on longer term care of complex cases. Some of our members, who have received a clinical diagnosis for adult ADHD, have struggled for many years with the condition undiagnosed, while also drawing resources from the NHS for depression and other mental health complaints such as borderline personality disorder. Correct treatment of adult ADHD can bring about substantial changes and facilitate people taking charge of their own mental health.

Adults with previously undiagnosed ADHD, often first go to their GP with depression or anxiety issues and by not identifying and treating the underlying ADHD, the recovery of these individuals is severely hindered or prevented. There is a clear policy gap around ADHD in adults in Scotland, which we are asking the Government to address urgently. This important issue has not been considered by Government before.

## Petition background information

ADHD is a neurodevelopmental disorder resulting in difficulties in three key areas of functioning: impulsivity, inattention and hyperactively/restlessness. It is a genetic condition where, in many cases, the outcome can be positively or negatively affected by the person's environment. Commonly considered to be a childhood condition, in 15% of cases the full diagnosis can still be applied at age 251. Debilitating symptoms persist

into adulthood in 65% of cases<sup>1</sup> and are often associated with depression or anxiety, mental health issues, addictions, obesity, criminal behaviour and/or high risk pursuits with increased incidence of accidents and driving convictions. Prevalence rates are reported by NHS Scotland as 3-9% of school-age children and young people and 2% of adults<sup>1</sup>. In Scotland approximately 0.6% of school-aged children and young people are diagnosed with the condition and an indeterminately low percentage of adult patients, indicating that the condition is grossly under diagnosed. It does not develop in adulthood, though many adults can be undiagnosed in childhood, seeking support and treatment in adulthood after symptoms make their lives impossible to manage.

Although adult ADHD is a well documented condition, it remains little understood and resourced in Scotland<sup>2</sup>, which lags behind the rest of the UK, evidenced by the lack of integrated clinical pathways and specialist clinics, which are in place in England <sup>3</sup>. The NHS in Scotland is failing to provide appropriate specialist resources and facilities for the many undiagnosed adults in the population, and for young people with the condition who reach adulthood and are then left unsupported; often falling prey to addictions, long term joblessness, depression, lack of education, homelessness, and problems with the law.

Adults with ADHD face substantial difficulties in accessing assessment by those with the appropriate level of skill and expertise. There is clear evidence that undiagnosed and untreated adult ADHD in the population imposes huge costs on society.<sup>4, 5</sup> The impairments suffered are not trivial, they include increased risks of accidents, substance misuse, mood disorders and antisocial behaviour, poor academic and occupational histories, poor inter-personal relationships and increased risk of relationship difficulties and breakdown. <sup>6, 7</sup> In 2009 the Chief Medical Officer for Scotland said that “adult ADHD services in Scotland are at best an unfamiliar diagnosis and at worse its existence is denied.” <sup>8</sup>

It is widely accepted that there are considerably higher levels of addiction, marital breakup and homelessness among adults with untreated ADHD, yet the treatment, by medication and other means, can be effective in helping with the condition. The social and economic costs of failing to provide a proper clinical pathway for adults with ADHD are immense. We ask the Parliament and Government to address this issue urgently. The lack of ADHD services for adults in Scotland is a matter of discrimination and inequality which we believe contravenes the Equality Act 2010 (Statutory Duties) (Scotland) Regulations 2011.

Even though adult ADHD is not at present formally addressed by NHS Scotland, we believe they must acknowledge there is recognition given to adult ADHD by the NHS in England and Wales and therefore adult ADHD will have to be included in the consultation on a mental health for Scotland (2011-15) <sup>9</sup> and provided with a specific integrated clinical pathway which must encompass the range of severity in ADHD and ensure that the appropriate help is identified and implemented.

#### References:

1. NHS Inform. Attention deficit hyperactivity disorder (ADHD). [www.nhsinform.co.uk](http://www.nhsinform.co.uk), accessed 12/08/2011.
2. NHS Scottish Intercollegiate Guidelines Network (SIGN) Guideline 112. (2009) Management of attention deficit and hyperkinetic disorder in children and young people.
3. NHS National Institute for Health and Clinical Excellence (2008) Diagnosis and management of ADHD in children, young people and adults (England only).
4. McCarthy et al (2009) ADHD treatment discontinuation in adolescents and young adults. *Journal of Psychiatry* 195(3):273-277.
5. Young S et. al (2009) ADHD and critical incidence in a Scottish prison population. *Personality and Individual Difference* 46(3):265-269.
6. Coghill, D. (2004) Understudied and under-recognised. *Adv. In Psychiatric Treatment* (10) 338-340.
7. Editorial (2011) Adults with ADHD: ignored and under-treated. *Drug and Therapeutics Bulletin* (49) 7: July 2011.
8. NHS Scotland (2009) Annual Report of the Chief Medical Office. December 2009

p27.

9. Scottish Government (2011). Consultation on a mental health strategy for Scotland 2011-15.

**Unique web address**

<http://www.scottish.parliament.uk/GettingInvolved/Petitions/PE01402>

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1

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