The Diagnosis & Management of ADHD.

[CONSENSUS STATEMENT ON THE DIAGNOSIS AND MANAGEMENT OF ADHD]
The Ulster Paediatric Society, The British Association of Community Child Health and The Royal College of Psychiatrists in N.I. Child & Adolescent and Intellectual Disability Faculties.
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(i) **INTRODUCTION.**

The National Institute of Clinical Excellence (NICE) recommends that children with suspected ADHD should be referred to an appropriate specialist in secondary care including Paediatricians and Child Psychiatrists. Following a meeting of the Ulster Paediatric Society and Child & Adolescent Faculty of the Royal College of Psychiatrists, N.I. Division it became apparent that ADHD services in Northern Ireland vary a lot in what is offered and it was decided to set up a clinicians working group to develop a consensus statement on the diagnosis and management of ADHD in children and adolescents. This group was later extended to include the British Association of Community and Child Health and the Intellectual Disability Faculty of the College.

It should be emphasized that such variation in practice and provision is not unique to NI. Attitudes and practice vary widely across the UK. In Scotland prescription rates for stimulants vary sevenfold among health boards (1). A 2010 CAMHS needs assessment document from Norfolk revealed that despite the work on an ADHD service and pathway for Norfolk this was one of the most widely reported gaps in service, with concerns about a lack of early intervention, a high use of medication, inequitable access to psychology input, poor access to other therapies or interventions being noted in a number of interviews with stakeholders (2).

The NICE clinical guideline 72 (2008) on the diagnosis and management of ADHD in children, young people and adults (hereafter NICE CG 72) highlights that the evidence suggests referral pathways for ADHD can be complicated. Diagnosis and the provision of treatment for children is varied, as is the way services are organised. Multi-agency working in relation to ADHD is considered to be deficient.

The consensus statement will focus on both clinical & service issues and will aim to ensure:
- Consistent implementation of the NICE guidelines across the NI region
- The development & sharing of best practice
- Clinical leadership with regard to future service re-design & development.

(ii) **ASSESSMENT, DIAGNOSIS AND TREATMENT.**

A recent study of the clinical decision making process of 50 Paediatricians and Child Psychiatrists from the South of England and Belgium found that guidelines were not at the forefront of the diagnostic process (3). Clinicians rarely specifically referred to any published guidelines as informing their diagnostic or treatment decision. This is not to say that guidelines are not followed; they may be used implicitly. When mentioned, guidelines were often criticized for failing to capture the realities of working with complex, challenging, and diverse client groups. With this caveat in mind the NICE guideline will be the basis for recommendations the working group makes.

NICE CG 72 states that “determining the severity of ADHD is a matter for clinical judgement, taking into account severity of impairment, pervasiveness, individual factors and familial and social context. Symptoms of ADHD can overlap with those
of other disorders, and ADHD cannot be considered a categorical diagnosis. Therefore care in considering the differential diagnosis is needed. ADHD is also persistent and many young people with ADHD will go on to have significant difficulties in adult life.”

NICE CG 72 continues, “Drug treatment for children and young people with ADHD should always form part of a comprehensive treatment plan that includes psychological, behavioural and educational advice and interventions.” The guidelines make it clear that new diagnoses of ADHD can be made up to the age of 17 and that accordingly services should be available to meet the demand. Treatment and management is required throughout adolescence and into adulthood (4).

Clinicians have the difficult task of weighing up numerous sources of information when making decisions regarding the diagnosis and treatment of children presenting with ADHD symptoms. Assessment involves consideration of whether there are alternative causes for restless, inattentive and impulsive behaviour and whether co-morbid conditions are present. Information must be collected from multiple sources to effectively manage discrepant or contradictory accounts of the child. A diagnosis is more likely to be made when clinicians are confident that symptoms and behaviour exhibited by the child are not a function of a parenting style which does not provide consistent, clear boundaries, a sub-optimal home/school environment, or other conditions. While referrals may often look straightforward, complexity tends to emerge over time. It is important that comprehensive social assessments are carried out as part of an overall ADHD assessment and clinicians should have access to social work assessments particularly for complex cases or those where family / systemic factors are felt to be contributing to the overall presentation.

Management involves liaising with schools and considerable time can be taken up in coordination of services. On-going review of a management programme and medication is required as the child gets older and transfer between Paediatric and specialist CAMH and Adult Mental Health services can be difficult. NICE clinical guideline CG72 notes that children and young people with ADHD would benefit from improving organisation of care and better integration of Paediatric, CAMHS and Adult services. It should be noted that Tier 3 CAMHS are not tertiary medical services; Tier 3 CAMHS are secondary care services and tier 2 primary mental health workers provide a link between primary and secondary care. Tertiary services are specialised services only available on a regional basis. Therefore ADHD is very much within the remit of Tier 3 CAMHS. Adequate & robust ADHD assessment is time intensive and Trusts need to ensure that multidisciplinary teams are adequately resourced. The development of specialist nursing roles, social work practitioners and psychological assistants can be helpful in this regard.

Current Situation in N. Ireland. Examples of good practice in NI were noted within Paediatrics, CAMHS and Children’s L.D. services. Paediatricians offer a strong medical and developmental perspective and have close relationships with AHP’s such as Occupational Therapists. Psychiatrists offer a psychosocial perspective and the ability to manage co-morbid mental health difficulties. The Bamford Review of CAMHS in NI (2006) stated that Community Paediatric and Specialist CAMHS should agree and develop clear referral pathways and guidelines for the assessment and treatment of ADHD. It noted that when resources permit, joint clinics should be developed for assessment and management of the more complex cases.
The working group recognises the need for closer working relationships between Child Psychiatrists and Paediatricians in NI. The group believes that Paediatricians and Child Psychiatrists should attempt to approximate to the same general approach to the assessment and management of these children (subject to potential barriers being identified and remedied).

The working group considers that the best way to ensure consistency of services would be to establish a single point of access in each Trust for ADHD referrals aged 5 -17. Assessment teams should consist of clinicians from both Paediatrics and CAMHS and when required Learning Disability Services who would conduct initial assessments over a minimum of 2 appointments. This would include liaising with teachers and other involved professionals to gather all necessary information. Straightforward cases could be diagnosed in a minimum of 2 appointments and subsequently managed within Paediatric Services. Cases requiring Occupational Therapy input may best be managed through Paediatric Services but children being seen in CAMH services should also be able to access OT - see also section v (b). Cases with significant mental health co-morbidities and where e.g. family therapy is required and older adolescents could be managed through CAMHS. It would be anticipated children may require moving between Paediatrics and CAMHS services and establishing a joint clinic would facilitate both initial diagnosis and their subsequent management.

**Recommendation:** Trusts should establish a single point of access referral system for assessment of ADHD.

(iii) **AIDS TO ASSESSMENT.**

Similar tools to aid assessments e.g. Strengths and Difficulties Questionnaire (SDQ) and Conner’s 3 should be used by all assessment teams. The SDQ has online scoring and Conner’s 3 has computerised scoring aids and teams should also consider Continuous Performance Test aids which are now easily available at modest cost to increase accuracy of diagnosis in more complex cases. For children with intellectual disability, it is important to be able to assess their level of functioning e.g. ABAS.

**Recommendation:** Trusts should provide ADHD teams in CAMHS and Paediatrics with computerised scoring systems and Continuous Performance Tests to aid the assessment process.

(iv) **PHARMACOLOGICAL TREATMENTS.**

Medication has been long recognised as having a central role to play in the treatment of ADHD. It is not considered necessary to further discuss its place in this document as guidance on its use is well documented in the NICE guidelines. The post-diagnostic management of ADHD requires that shared care arrangements according to the Northern Ireland Interface Pharmacy Guidelines should be in place. It should be clearly established who holds responsibility in each case for physical monitoring e.g. height, weight and blood pressure.
(v) NON-PHARMACOLOGICAL TREATMENTS.

It is imperative that practitioners working in the area of ADHD are adequately trained and resourced to provide psychological interventions as recommended by NICE clinical guideline 71. This includes:

- Parent-training/education programmes (as above)
- Individual or group treatments for young people: CBT and social skills training.

(a) Parent training:

NICE CG 72 states that families or carers should be offered an assessment of their personal, social and mental health needs. They should be encouraged to participate in support and self-help groups if appropriate. They should be advised about positive parent and carer-child contact with clear and appropriate rules about behaviour and structuring the child or young person’s day. The guideline states that it should be emphasized that parent-training/education programmes aim to optimise parenting skills to meet the above-average parenting needs of children and young people with ADHD and do not imply a lack of a parenting skill.

Parenting programmes should include help for parents to regulate their own emotions. When parents are able to regulate their own expression of emotion, show supportive reactions to children’s expression of negative affect and discuss and coach children around emotion, children show better emotional competence including greater emotional awareness and emotion regulation abilities (5). Parent training should be offered on an individual basis if this is preferred. All children and families affected by ADHD should have access to parent training provided by suitably trained practitioners.

Current Situation in N. Ireland. Parent Training seems to be lacking in HSC Trust provision in NI. At least one Trust CAMHS team has been using the Parent Plus training programme but apart from this there is no consistent on-going use of evidence based programmes such as recommended by the NICE guideline (Webster Stratton or Triple P). Some Education & Library Board Behaviour Management teams have run the Webster Stratton “Incredible Years” programmes. Some Voluntary Sector groups run excellent parenting programmes. Parents should have the opportunity to attend a structured 8 – 12 week programme of manualised, evidence-based parent training sessions which will focus on improving both the child’s behaviour and the parent-child relationship.

Recommendation: Group-based programmes developed for the treatment and management of children with conduct disorder should be available across all Trusts in NI to parents or carers of children with ADHD whether or not the child also has conduct disorder (see also Section viii, the Role of Primary Care).

(b) Individual, family or group treatments for young people:

Children with ADHD often have motor co-ordination & sensory processing difficulties. Occupational Therapists have a significant role in managing motor problems e.g. in DCD (“dyspraxia”) providing strategies to help self-organisation and also sensory processing strategies especially in co-morbid attachment and autistic disorder.
Children with ADHD should have access to OT whether they are being managed in a Paediatric or a CAMHS setting.

CBT and social skills training. Clinical Psychologists can run and supervise behavioural management programmes (individual or group) and offer individual CBT but their availability to work with children with ADHD in Paediatric and CAMHS services varies across the province. Children & Young people should be able to access individual or group psychological interventions whether or not they have co-morbid mental health problems and whether or not they are being treated primarily with Paediatrics or CAMH.

When children and families present with significant co-morbid mental health problems or family stress they should be able to access relevant supports and interventions within CAMHS including Family Therapy or attachment-based interventions, often these will be provided by social work practitioners.

**Recommendation:** Trusts should ensure access to appropriate non-pharmacological individual or group treatments for children and adolescents with ADHD.

**(vi) ROLE OF SPECIALIST NURSES.**

The role of nurse specialists is currently better developed within CAMHS but does exist in Paediatric clinics in some areas. It can include medication monitoring, parent training interventions and behavioural advice for parents and children. Nurse prescribing is not as yet widely established in NI services but this is a possible future development; where nurse prescribers have developed ADHD clinics these are working well.

**Recommendation:** Specialist Nurse Practitioner posts should be established in Paediatric and Learning Disability services as well as CAMHS services.

**(vii) DIAGNOSIS IN INTELLECTUAL DISABILITY.**

The diagnosis of ADHD can be difficult but important to make in children with intellectual disability. It is important that ‘diagnostic overshadowing’ doesn’t mean that significant ADHD is left untreated. Clinicians should have training to recognise how ADHD presents in children with severe I.D. e.g. more emphasis on “fitting and fleeting activity”. There is an increased incidence of ADHD in various genetic disorders e.g. Angelman’s. When making the diagnosis, standardised rating scales e.g. Conner’s are not validated for use in the I.D. population and will yield false positives. Behavioural difficulties are more likely to be complex and children and young people should have access to individual behavioural interventions which will include communication strategies. Children with I.D. who have ADHD are more likely to have seizure disorders and other associations such as cardiac problems so joint management from Paediatrics and CAMHS/I.D. services is desirable. This is an area where the role of the nurse specialist is particularly important. Children with I.D. should be able to access the single-point of referral when deemed useful by their treating clinician.
Consensus Statement on the Diagnosis and Management of ADHD

**Recommendation:** Children with intellectual disability should have access to ADHD services delivered by appropriate specialists in secondary care, including referral through the single point of access as necessary. This will require joint working between Paediatrics and specialist I.D. services (with clients moving between services, with similar arrangements to those described above for children accessing mainstream CAMHS). Joint management between Psychiatrists, Nurse practitioners and Paediatricians will be particularly important for children with complex medical difficulties e.g. epilepsy.

**(viii) THE ROLE OF PRIMARY CARE.**

ADHD should only be diagnosed by Specialists in Secondary Care. Parents who have concerns about their children’s behaviour can present to a range of Primary Care Services including G.P. and Health Visitor, Social Services or Education Services e.g. Special Educational Needs Coordinator. NICE recommends that primary care practitioners should determine the severity of behaviour and / or attention problems suggestive of ADHD and how they affect the child or young person and their parents or carers in different domains and settings.

NICE recommends that where behaviour and / or attention problems are having an adverse impact on the child’s development or family life, parents / carers should be offered a referral to a parent training / education programme. If the behavioural and / or attention problems persist with at least moderate impairment, the child or young person should be referred to secondary care for assessment. However, if a child / young person’s behaviour and / or attention problems are associated with severe impairment, a referral should be made directly to secondary care.

As the majority of referrals from the Primary Care sector in relation to diagnosing or confirming ADHD are from GPs then it will be important for them to be kept up to date on the appropriate recognition of symptoms and referral process to Secondary Services and what is provided therein within their respective Trust. A pathway for post diagnostic management including shared care arrangements for drug prescribing and community dispensing needs to be clearly identified.

**Current situation in N Ireland:** Most referrals of children / families to Secondary Care, where the underlying reason for referral is behavioural problems, have not had prior referral to parent training / educational programmes. Parents have not received individual or group parenting advice and support around behaviour management (e.g. positive parenting, importance of routines and consistency in parenting approaches). This would prevent a number of inappropriate referrals.

**Recommendation:** Trusts should have in place a robust system for providing parent-training / education programmes when a need is identified within Primary Care and supported by wider social and educational services. Children and young people should only be referred to secondary care if they present initially with severe impairment or where moderate impairment persists after parent-training / education has been provided. Clear arrangements for post diagnostic management,
(ix) TRANSITION TO ADULT SERVICES.

Over the years ahead there is likely to be an increase in numbers of referrals of adults with ADHD to mental health services, both ‘graduates’ from children’s services and adults seeking diagnosis. It is unlikely that current services will be able to address the growing demand. Various models of service provision are developing across the U.K., recognising the need for specialist and comprehensive input to continue into young adulthood and for transition from CAMHS to be seamless.

Current situation in N Ireland: There are no formal services for ADHD in Adult Mental Health services in NI though some Adult Psychiatrists in some Trusts will take over the care of patients from CAMHS teams on a case by case basis. In some Trusts children with ADHD are discharged from Paediatricians to the care of their GP as no dedicated adult service is available. It is usually easier for CAMHS Consultants to arrange transition to Adult Mental Health services but too often this depends on good personal relationships. The working group considers this to be an unsatisfactory situation.

Recommendation: Formal arrangements for transfer of young adults with ADHD to Adult Mental Health services should be developed in each Trust. Adult Mental Health services in every Trust should develop services, with dedicated practitioners, who will provide specialist input for adults with known or suspected ADHD. The relevant college faculties should consider publishing an addendum to this document with detailed recommendations.

(x) TERTIARY SERVICES.

It should be noted that there are no Tertiary ADHD services available within N.I. which comprises the full implementation of NICE CG 72 (e.g. the use of unlicensed treatments when there is a poor response to 1st & 2nd line treatments).

Recommendation: A regional Tertiary service for very complex ADHD cases should be developed.

(xi) SERVICE DESIGN AND IMPLEMENTATION.

The NICE CG 72 states that every locality should form a multi-agency group, with representatives from multidisciplinary specialist ADHD teams, Paediatrics, Mental Health and Learning Disability teams, Forensic services, CAMHS, the Children and Young People’s Directorate including Education and Social Services, Voluntary sector parent support groups and others with a significant local involvement in ADHD services. The group should:

- Oversee implementation of the guideline
- Start and coordinate local training initiatives, including training and information for teachers about the characteristics of ADHD and its basic behavioural management.
- Oversee the development and coordination of parent-training/education programmes.
- Consider compiling a comprehensive directory of information and services for ADHD including advice on how to contact relevant services and assist in the development of specialist teams.
- Multi agency working needs to be valued as integral part of duties as it facilitates a variety of interventions but requires effective communication, a common language to express CAMHS concepts, mutual understanding & respect and an ability to work across boundaries. Multi-agency collaboration should be measured in much the same way as face-to-face work.

Current Situation in N Ireland. The working group is not aware that to date any such multi-agency groups addressing ADHD have been formed in NI.

Recommendation: Each Trust should establish an ADHD multi-agency group.

(xii) EDUCATIONAL PROVISION.

Working closely with education colleagues – teachers and Educational Psychologists is essential. Children with ADHD are much more likely to have learning difficulties and incur higher educational costs than children without ADHD. Both General & Specific Learning Difficulties are over-represented in children with ADHD: up to 50% struggle with specific learning problems e.g. literacy difficulties. They are more likely to have Processing Speed problems (i.e. reduced ability to process simple / routine visual information efficiently) and problems with Working Memory. Educational Psychology advice can be of help with these difficulties.

Current situation in N. Ireland. Collaboration with Educational Psychologists is generally good but working relationships need to be strengthened across the region. Education Board Behaviour Management Teams can be of great help in managing behaviour in children with ADHD in schools and links with them should also be strengthened.

Recommendation: Existing good links with Education Board services should be strengthened through the establishment of multi-agency groups.

(xiii) VOLUNTARY SECTOR GROUPS.

NICE CG 72 states that families or carers should be encouraged to participate in support and self-help groups if appropriate. In the Belfast area ADDNI offer this kind of support but it is less easy to access from outside the Belfast area. Other areas have had support groups that have been started by parents and groups as Parent Advice Centre, New Life Counselling (Belfast) and others offer excellent parents’ behaviour support groups.

Recommendation: Voluntary sector groups should be represented on Trust Multi-agency Groups.
(xiv) **COMMISSIONING.**

The working group is not aware that services for ADHD have been specifically commissioned in NI. The NICE Commissioning Guide (2009) states that the potential benefits of robustly commissioning an effective service for the diagnosis and management of ADHD in children and young people include: **improving and recognition, accurate diagnosis and treatment of ADHD in children and young people** and limiting the impact of late initiation of treatment, undiagnosed and untreated ADHD.

**Recommendation:** The HSC should specifically commission ADHD services in NI.

(xv) **AUDIT AND RESEARCH.**

Audits of services run by Paediatricians and CAMHS teams were presented at the meeting of UPS, BACCH & RCPsych NI Cap Fac in May 2012. While these were very valuable there was evidence of a lack of integration of services and services operating with little reference to those run by the other discipline in the same area.

ADHD services should continue to improve based on feedback, outcome measures and multidisciplinary audit.

**Recommendation:** Audit and research should be developed on a local basis in line with the recommendations of NICE Clinical Guideline 72.
REFERENCES

(4) CAMHS Norfolk Needs Assessment (ibid) ‘Developing an ADHD Service for Adolescents: It’s not just about the drugs’ “There is significant reduction in services access between the age of 12 and 18 years …..in adolescence it is common to develop co-morbid disorders such as depression, substance misuse and self-harming. Therefore, it would appear that we are providing young people as accessing the least amount of support at a time when it is needed most. If we also take into account the lack of a full adult service for ADHD, this is of great concern.”