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## Classification, prevalence and integrated care for neurodevelopmental and child mental health disorders: A brief overview for paediatricians

Michael O Ogundele, Michael Morton

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### Abstract

'Neurodevelopmental disorders' comprise a group of congenital or acquired long-term conditions that are attributed to disturbance of the brain and or neuromuscular system and create functional limitations, including autism spectrum disorder, attention deficit/ hyperactivity disorder, tic disorder/ Tourette's syndrome, developmental language disorders and intellectual disability. Cerebral palsy and epilepsy are often associated with these conditions within the broader framework of paediatric neurodisability. Co-occurrence with each other and with other mental health disorders including anxiety and mood disorders and behavioural disturbance is often the norm. Together these are referred to as neurodevelopmental, emotional, behavioural, and intellectual disorders (NDEBIDs) in this paper. Varying prevalence rates for NDEBID have been reported in developed countries, up to 15%, based on varying methodologies and definitions. NDEBIDs are commonly managed by either child health paediatricians or child/ adolescent mental health (CAMH) professionals, working within multidisciplinary teams alongside social care, education, allied healthcare practitioners and voluntary sector. Fragmented services are common problems for children and young people with multi-morbidity, and often complicated by sub-threshold diagnoses. Despite repeated reviews, limited consensus among clinicians about classification of the various NDEBIDs may hamper service improvement based upon research. The recently developed "Mental, Behavioural and Neurodevelopmental disorder" chapter of the International Classification of Diseases-11 offers a way forward. In this narrative review we search the extant literature and discussed a brief overview of the aetiology and prevalence of NDEBID, enumerate common problems associated with current classification systems and provide recommendations for a more integrated approach to the

nosology and clinical care of these related conditions.

**Key Words:** Neurodevelopmental disorders; Mental health disorders; Adolescents; Child health; Mental health services; Emotional problems; Behavioural problem; Sub-threshold diagnosis; Sleep disorders; Integrated care

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**Core Tip:** Neurodevelopmental, emotional, behavioural, and intellectual disorders (NDEBID) in this paper refers to many congenital or acquired long-term neurodevelopmental, neurological or muscular disorders, with the often co-occurring mental health disorders presenting in Community Child Health or child/adolescent mental health settings. This paper provides a brief overview of the aetiology and prevalence of NDEBIDs, highlights common problems associated with the current classification systems and aims to stimulate discussion among professionals towards consensus agreement on how best to classify the NDEBIDs. It makes a strong case for integrated care between paediatric and mental health services for optimal assessment and management of children and young people with NDEBIDs.

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## INTRODUCTION

Childhood mental health and neurodevelopmental disorders are very common and represent a significant public health challenge. These disorders encompass a wide range of clinical entities of diverse aetiologies and pathogenesis. There are arguments for and against the clinical utility of a paediatric approach of grouping the emotional and mood disorders arising in childhood and adolescence (including anxiety and depression), neurobehavioural disorders [including attention deficit hyperactivity disorder (ADHD)], neurodisabilities [including cerebral palsy, epilepsy, autism spectrum disorder (ASD) and sensory processing disorders] with the typical neurodevelopmental disorders (such as intellectual and language disorders), considering their complex aetiologies and pathogenesis[1-5]. Some researchers have argued for the use of the term Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations, to encourage the early identification of neurodevelopmental, emotional, behavioural, and intellectual disorders (NDEBIDs) in vulnerable children (*e.g.*, those exposed to abuse or neglect) leading to multidisciplinary evaluations and potentially long-term follow-up by paediatricians, psychologists, speech therapists and other allied health care professionals[6-9]. Children and young people (CYP) with mental health and neurodevelopmental disorders are usually seen by teams in Community Child Health (CCH) services (with paediatricians and allied health professionals - physiotherapists, occupational therapists, speech and language therapists, dieticians and specialist nurses) or child and adolescent mental health service (CAMHS) with psychiatrists, psychologists, therapists, nurses and social workers. They also need to work closely with other multi-agency teams with professionals from social care, education, the voluntary sector and allied healthcare practitioners.

Mental health disorders (MHD) including behavioural and emotional problems, anxiety, depression, substance misuse disorder, eating disorders, self-harm, post-traumatic disorders, bipolar disorder, schizophrenia and some developmental disorders (often including autism and ADHD) among other difficulties are usually managed by the CAMHS teams[10]. MHDs are common and increasing in the United Kingdom child and adolescent population[11], leading to pressure on CAMHS. CAMHS in the United Kingdom may set boundaries to manage their work stream and if services decline referrals these may remain with CCH[12].

CCH paediatricians are specialists managing CYP with neuro-behavioural and neurodevelopmental disorders, disabilities, those with complex health needs (including end of life care), special educational needs, safeguarding, child sexual abuse, child public health[13]. They form part of integrated teams involving the education, social care and voluntary sectors[2,9,14]. The range of services offered within the CCH is variable across the United Kingdom with each team providing a unique range of statutory and non-statutory functions[13]. CCH paediatricians invariably have to deal with CYP with MHD and behavioural problems as they work with child safeguarding services or CYP under the care of the public system[9,15]. However, they are less likely to regard themselves as having expertise to manage “mental health” disorders and may avoid making some mental health diagnoses. Nevertheless, some common

MHDs including presentations that may fall below the threshold of clinical diagnoses are commonly managed under the care of CCH including self-harm, substance misuse and attachment difficulties.

In this paper, we have taken the pragmatic approach of referring to the CYP who are likely to come under the radar of joint care between CCH and CAMHS as having NDEBID. Different terminologies of “disorders”, “difficulties” and “problems” may be used when referring to childhood NDEBID conditions. We will restrict ourselves to the “disorder” terminology in this paper.

Classification systems for childhood MHD continue to receive considerable attention from three main global professional bodies, including the World Health Organization (WHO), the American Psychiatric Association (APA) and the United States National Institute of Mental Health, using both varying and overlapping frameworks[16]. Their latest publications respectively, the eleventh revision of the international classification of diseases and related health problems (ICD-11), the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and Research Domain Criteria (RDoC), constitute the most widely used standardised classification systems used by researchers and clinicians worldwide. Revision of these classification systems has been accompanied by vigorous debates in the scientific literature, among clinicians and health advocates, and in the lay media[17]. Though the RDoC system is not intended for immediate clinical use, it provides a basis for research framework which accommodates the study of all causal factors together including the neurological, biological, psychological, social, and cultural structures and processes that underlie mental illness broadly[16].

This narrative review documents findings from a search of the extant literature and discusses a brief overview of the aetiology and prevalence of NDEBIDs, enumerate common problems faced by clinicians in reference to the current classification systems and management of common NDEBIDs and proffers some recommendations for addressing these problems. The content derives from a review of relevant published literature indexed by Ovid, pubmed, pubmed medical central, CINAHL, Embase, Database of Abstracts and Reviews, and the Cochrane Database of Systematic reviews and other online sources, with relevant themes identified.

We note an argument for bringing sleep disorders under the same wider umbrella with NDEBID. We make a case for a more integrated approach to the nosology and clinical care of these related conditions. We also argue for the necessity of simultaneous interventions for the total profile of difficulties and impairments that accompany the primary diagnosis, even if these do not reach the required threshold for a so-called comorbid diagnosis.

### ***Genetic and environmental causes of NDEBIDs***

Though the exact causes of various NDEBID are unknown, studies have identified a complex interplay between genetic vulnerability and adverse environmental factors that increase the risk of developing any of these disorders. These include perinatal, maternal, family, parenting, socio-economic, biologic and personal risk factors. Genetics can play an important role in many neurodevelopmental disorders, and some cases of certain conditions such as intellectual disability are associated with specific genes. There are many genetic causes of intellectual disabilities such as Down's, Prader-Willi, Williams and Fragile X syndromes. The co-existence of disorders and the development of one problem into another raise important research questions, such as the possibility of shared aetiologies and risk factors associated with heterogeneous phenotypes[18,19].

The evidence is clear that the early years are critical for brain development, with a profound impact on children's cognitive, social and emotional development, which affects them into later life[20]. Maternal use of alcohol, tobacco, or illicit drugs during pregnancy and more subtle effects such as maternal stress or anxiety; exposure to socioeconomic adversity; parental maladaptive behaviour; childhood exposure to abuse and inter-parental violence; cognitive ability, and affiliation with deviant peers in early adolescence have been shown to predispose to childhood behavioural disorders[21,22]. Other risk factors include preterm birth; low birthweight and the effects of nutrition[23] and chronic disease[24] on child development. Lead, methyl-mercury, and polychlorinated biphenyls are widespread environmental contaminants associated with adverse effects on a child's developing brain and nervous system in multiple studies[19]. Effects of adverse prenatal adverse factors are mediated in the foetus by stress hormones such as cortisol. However, it is often difficult to say definitively what constitutes a risky level of prenatal exposure for any given child[25].

### ***Global prevalence of NDEBID conditions***

The global rate of mental disorders among CYP aged 5-17 years has been estimated to be 6.7% (including conduct disorders: 5.0%, ADHD: 5.5%, ASD: 16.1%, depression: 6.2%, anxiety: 3.2%)[26]. In England, rates are increasing; one in eight (12.8%) 5-19 years old had at least one MHD assessed in a 2017 study, with 17-19 years old girls having the highest prevalence rate of one in four (25%). Rates of emotional disorders (anxiety and depression) showed the biggest increase, from 3.9% in 2004 to 5.8% in 2017[11]. Rates have increased further during the coronavirus disease pandemic to rates of 1 in 6 of 5-16 years old with a probable mental disorder (2020-wave-1-follow-up). Limited consensus among clinicians and researchers about the classification of the various NDEBID conditions has hampered universal comparison of service-based research findings and population-based studies[27]. A wide range of prevalence rates for NDEBIDs have been reported in developed countries, up to 15% of children's population), including up to 10% prevalence for developmental delay[28-30]. The commonest childhood



neurodevelopmental disorders are ADHD, ASD, tic disorders (TD)/Tourette's syndrome (TS), intellectual (learning) disability (ID), developmental delay and developmental coordination disorder (DCD)[2]. ADHD is the commonest childhood neuro-behavioural disorder, affecting up to 5% of school-age children. Reported prevalence of these conditions varies (for example, prevalence of DCD from 1.5% to 20% depending on how it is defined)[31]. Conflicting prevalence rates have been reported in both developed and developing countries worldwide, due to differences in study methodology and definitions used[27]. Table 1 shows the wide range of reported prevalence rates for a selected group of NDEBIDs, including some extreme cases such as attachment difficulties and disorders, where there are differences in terminology that lead to apparent variations in prevalence up to 100 times or more.

### **Evidence-based assessment**

Diagnosis of most NDEBIDs remains primarily clinical, based on detailed history-taking as well as observation of a child's appearance and performance. This should include general medical, developmental, family, social, educational and emotional history. Physical and neurological examination should include assessment of vision, hearing, dysmorphic features, neurocutaneous stigmata, motor skills, mental state and cognitive assessment. Condition-specific and generic observer feedback on rating scales and questionnaires can be used to complement direct clinical observations to arrive at a diagnosis.

There is no single diagnostic tool available for the confirmation of childhood behavioural disorders. Diagnosis is usually based on various combinations of more or less subjective reports of parental, teacher, professional or other observer feedback on a variety of psychometric questionnaires or screening tools[32] and all such assessments may be prone to biases. There is often a marked discrepancy between various respondents giving feedback on screening questionnaires. The published literature suggests that parents often report more symptoms and diagnoses of oppositional defiant disorder (ODD) and conduct disorder than teachers, and parent-teacher agreement is often low except when behaviour report feedback is obtained within the same context[33].

There are several well validated screening tools that are designed to identify children and adolescents who are at-risk of having MHD and/or those who would most benefit from more in-depth assessment [34]. These have potential usefulness in early identification of NDEBIDs among vulnerable groups of CYP, leading to effective interventions[9]. There are also many established rating scales and clinical instruments to assess NDEBIDs (*e.g.*, the Autism-Tics, ADHD, and other Co-morbidities inventory is reported to have a good to excellent sensitivity and specificity[18]).

Recent advances in computerized Continuous Performance Task (CPT) tests have greatly improved their clinical utility in the assessment of some NDEBIDs[35]. Such objective representation of the symptoms of NDEBIDs visually presented with the aid of diagrams and graphs, could enable parents, and often patients, to gain a better understanding of their condition and to better appreciate and comply with the medical management proposed by the clinician[36].

## **PROBLEMS ASSOCIATED WITH THE CURRENT CLASSIFICATION OF NDEBID CONDITIONS**

### ***Confusing terminologies: “Disorders”, “difficulties” and “problems”***

Some authors have questioned the differences in the use of terminologies of “disorders”, “difficulties” and “problems” when referring to childhood NDEBID conditions. Detailed discussion about the merits and demerits of each term is outside the scope of this paper. “Difficulties” or “problems” tend to be used in research or clinical settings where approved or validated diagnostic tools based on one or more classification systems for disorder diagnoses have not been formally used, but clinical impressions have been based on the experienced clinicians' appraisal of the CYP's profile of difficulties and multi-modal impairments[37,38]. Clinical expertise determines clinicians' use of diagnoses; paediatricians and psychiatrists each have areas of competence and these areas overlap incompletely (Figure 1). Another situation where the term “difficulties” may be preferred is in preschool children where the outcome of problems identified at an early stage is less certain. Challenging behaviours and emotional difficulties are common but these are therefore more likely to be recognized as “problems” rather than “disorders”, as it is thought that psychiatric diagnoses need to be used cautiously in the pre-school age group[39].

### ***Sub-clinical presentations and sub-threshold diagnosis***

NDEBID are often diagnosed by using various methods relying on observation and questioning such as compilation of sufficient numbers of symptoms and reaching thresholds on psychometric tests, with recognition of a specific impairment. Sub-threshold diagnoses (insufficient symptoms to make a diagnosis but some evidence of impairment) are common in CYP, and are clinically important in terms of predicting poorer adult mental health and functional outcomes[40]. A group of child development multidisciplinary professions have emphasized that “a specific diagnosis may not be identified” in many neurodisabilities[41]. It has been observed that children suffer some significant neurodevelopmental disabilities that may not reach the threshold for a specific diagnosis but still require compre-

**Table 1 The reported prevalence rates and some definition of neurodevelopmental, emotional, behavioural, and intellectual disorders conditions commonly seen in Community Child Health settings**

Categories/diagnosis	Characteristics	Reported prevalence	Ref.
All NDEBIDs	Four broad categories: emotional (8.1%), behavioural (4.6%), hyperactivity and other less common disorders	12.8% to 18%	[11, 30,85]
Behaviour difficulties/ disorders	Externalising disorders; Disruptive behavioural disorders (including ADHD, CD and ODD)	7.5 to 10%	[11, 32]
Attention deficit/hyperactive disorder	Pervasive symptoms, onset before age of 12, causing significant impairment and categorised into: (1) Predominantly inattentive; (2) Predominantly hyperactive-impulsive; or (3) Combined type	1% to 9%	[51, 86-88]
Autism spectrum disorder	Early onset, pervasive and persistent deficits in: (1) Social communication and social interaction across multiple contexts; and (2) Restricted, repetitive patterns of behaviour, interests or activities	0.76% to 3.5 %	[51, 89-91]
Emotional disorders	Internalising disorders; Including anxiety, depression and mood disorders	8.1%	[11]
Attachment difficulties/ disorders	Attachment difficulties include insecure attachment patterns and disorganised attachments, which can often evolve into coercive or compulsive caregiving patterns; Attachment disorders in DSM5: Reactive attachment disorder and disinhibited social engagement disorder; ICD-10 classification: Reactive attachment disorder and disinhibited attachment disorder	0.005% to 1.4% <sup>1</sup>	[7,85, 92]
Substance abuse	Someone who has ever taken drugs; Someone who has taken drugs in the last year; Someone who has taken drugs in the last month	7% to 37%: 11-15 yr; 20%: 16-24 yr	[93]
Self harm	A range of behaviours when someone hurts themselves on purpose	6.4% to 22%	[94-96]
All neurodisabilities	A group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations	3% to 15%	[41, 51,97, 98]
Visual impairments	Any cause of visual acuity to a level of 0.5 logMAR (6/18 Snellen) in each eye; Any specific visual processing, or eye movement problems <i>e.g.</i> , nystagmus	5.19 per 10000 (0.05%) to 5.7% <sup>1</sup>	[99-101]
Developmental coordination disorder	Early onset of coordinated motor skills is far below expected level for age; Motor skill difficulties significantly interfere with daily activities, academic/school productivity, prevocational and vocational activities, leisure and play; Not better explained by intellectual delay, visual impairment, or other neurological conditions that affect movement	0.8% to 6%	[31, 91, 102, 103]
Hearing impairments	Any hearing loss greater than 30 (or 35) dB in the better ear, including to glue ear (otitis media); Hearing loss: Reduced ability to hear sounds in the same way as other people at 20 dB or better; Hearing loss that adversely affects a child's educational performance	0.05 to 0.3%	[10, 51,71, 104]
Sensory processing disorder	A condition in which the brain and nervous system have trouble processing or integrating stimulus with 3 possible components: Sensory modulation disorder is a problem with turning sensory messages into controlled behaviours that match the nature and intensity of the sensory information; Sensory-based motor disorder is a problem with stabilising, moving or planning a series of movements in response to sensory demands; Sensory discrimination disorder is a problem with sensing similarities and differences between sensations; Not currently recognised as a distinct medical diagnosis	3.2% to 16%	[105-108]
Epilepsy	A disease characterized by an enduring predisposition to generate epileptic seizures and typical neurobiological, cognitive, psychological, and social consequences, fulfilling any of the following: (1) At least two unprovoked (or reflex) seizures occurring greater than 24 h apart; (2) One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 yr; (3) Diagnosis of an epilepsy syndrome	0.05% to 0.7%	[51, 109, 110]
Cerebral palsy	A neurological disorder of body movement and muscle coordination caused by a non-progressive brain injury or malformation that occurs while the child's brain is under development. Cerebral palsy primarily affects, with related intellectual disability, seizures; problems with vision, hearing, or speech; changes in the spine (such as scoliosis); or joint problems	0.1% to 0.4%	[51, 111]
Sleep difficulties/ disorders	Parent report of difficulty falling and/or staying asleep; Repeated difficulty with sleep initiation, duration, consolidation, or quality that occurs despite age-appropriate time and opportunity for sleep and results in daytime functional impairment for the child and/or family	3% to 36% <sup>2</sup>	[112, 113]
Foetal alcohol spectrum disorders	Group of disorders due to permanent brain damage in individuals exposed to alcohol during pregnancy resulting in a spectrum of physical, emotional, memory, language, behavioural and neurological impairments	0.77% to 6%	[114-117]
All developmental delays	Also called developmental disabilities or disorders; Group of conditions due to impairment in physical, learning, language, or behaviour areas beginning during the developmental period and may impact day-to-day functioning, and usually last throughout a person's lifetime; Any delay in	10% to 17% (5.7% to 7% in infancy)	[28, 29, 118]



	developmental milestones		[119]
Speech and language disorder/delay	Also called Specific language impairment; A communication disorder that interferes with the development of language skills in children who have no hearing loss or intellectual disabilities. It can affect a child's speaking, listening, reading, and writing	1.7% to 7%	[51, 120]
Intellectual (learning) disability	3 core criteria of reduced ability to understand new or complex information, impaired social independence, starting in childhood; Intelligence quotient of less than 70	2.1% to 3.6%	[121, 122]
Specific intellectual (learning) disability/disorder	Experience of any problems in a traditional classroom setting, including dyslexia, dyscalculia and generalized intellectual disability	1%	[51]
Global developmental delays	Delay in two or more developmental domains of gross/fine motor, speech/language, cognition, social/personal and activities of daily living; Used in early childhood suggesting need for specific diagnosis in later in life	1 to 3% (< 5 yr) to 12% by 9 mo	[28, 29, 118, 123]

<sup>1</sup>More than 100 times differences.

<sup>2</sup>More than 10 times differences.

NDEBIDs: Neurodevelopmental, emotional, behavioural, and intellectual disorders; ADHD: Attention deficit hyperactivity disorder; ICD: International classification of diseases; CD: Conduct disorder; ODD: Oppositional defiant disorder.

hensive assessments[42]. For example, the National Institute for Health and Care Excellence encourages professionals to recognize, assess and offer treatment for attachment difficulties in CYP who are in public care, many of which would not reach the threshold for formal diagnosis of reactive attachment disorder and disinhibited social engagement disorder, as defined in DSM-5 or ICD-11[38] which would typically only be diagnosed by a CAMHS teams[43].

One value of a diagnosis is that it enables confidence in using evidence-based interventions. Very little research is available to support psychiatric interventions when there is no diagnosis, even though most interventions are evaluated by the use of scales that measure change in dimensions of difficulty rather than a diagnosis changing. However excessive reliance on diagnostic labels can lead clinicians to focus on narrow checklists of symptoms, with little consideration of what is actually causing the patient's problems, thereby impeding holistic care and complete recovery of the patient[44]. Many authors have raised concerns about "unpredictable over-diagnosis" and "systematic medicalization of normality" due to overreliance on diagnostic labels[45].

Symptoms of co-morbidities not achieving the threshold for a diagnosis are an important source of heterogeneity that may be captured in RDoC for the purpose of research but are missed in classifications used in clinical practice. This highlights the need to extend clinical assessments beyond core diagnostic criteria; considering dimensions of symptoms, functioning, and social factors will lead to a more comprehensive management plan. If CYP have symptoms which fall just below the diagnostic threshold and are interfering with function, then interventions typically used for those diagnosed might be helpful.

There is still a need for better clinical classification of 'sub-threshold' presentations, which raises the question of how to gather and collate evidence for intervention in such cases. In ICD-11, this difficulty is partly addressed for some conditions (for example, the development of classification for personality traits, that do not reach criteria for a "disorder" diagnosis). However, the use of these categories has not yet been established in CAMHS. It might be argued that similar categories could be of value in other areas of classification, such as the specific neurodevelopmental disorders. The necessity of comprehensive assessment and simultaneous interventions for the total profile of difficulties that accompany the primary diagnosis, even if the comorbidities do not reach the required threshold for a specific diagnosis, has been emphasised[40].

### Conflicts within current classification systems

Classification of diseases involves the categorization of relevant concepts for the purposes of systematic recording or analysis based on one or more logical rules. Definitions of various childhood MHDs have not been consistent in the published literature and there is a wide overlap among various classification systems. The much wider terminology of neurodevelopmental, emotional, behavioural and intellectual problems has been suggested by some authors, emphasizing the overlap and common co-morbidity between Neurodevelopmental and MHD[9,30,46,47].

DSM-5 recognizes the place of neurodevelopmental disorders including ASD, ADHD, communication, motor and learning disorders within its classification of mental disorders and has a chapter for them[48]. However, other conditions that have their onset during childhood and adolescence, including conduct disorder and reactive attachment disorder, are located elsewhere in the manual.

The ICD-11 has a new chapter title "Mental, Behavioural or Neurodevelopmental Disorders" (06) grouping together many of the NDEBID including behavioural issues like ADHD, (conduct disorder and ODD), anxiety and mood disorders, developmental disorders including ASD, ID and specific conditions such as DCD with a link to the chapter on diseases of the nervous system (08) for TD/TS.

New diagnoses of gaming and hoarding disorders, as well as substance misuse disorders have also been brought under this chapter[49].

Sleep disorders have been brought together under a separate chapter in ICD-11 titled “Sleep-wake Disorders” (07), while epilepsy and cerebral palsy (often included in the definition of neurodevelopmental disabilities) are classified under a different chapter in ICD-11 (08) and are not coded in DSM-5.

### ***Peculiar case of sleep disorders***

It is well recognized that sleep problems are disproportionately more common among CYP with NDEBID and require particular attention in the clinic. Sleep disorders have been traditionally classified under different systems but now have their own chapter in ICD-11. Both the DSM-5 (APA 2013) and the International Classification of Sleep Disorders-third edition (ICSD-3)[50] are key reference standards for the diagnosis of sleep disorders. DSM-5 has 3 different categorical classifications for sleep disorders including “sleep-wake disorders”, “breathing-related sleep disorders” and “parasomnias”[48]. Other sleep difficulties including excessive daytime sleepiness, circadian rhythm sleep disorders and sleep-related movement disorders are also included. Similar terminologies are found in ICD-11. It is a welcome development that the DSM-5 and ICD-11 criteria for sleep disorders now mirror more closely the ICSD-3 classification system. This should enable a more consistent approach to the labelling of sleep disorders in the future. From a child health perspective, the common occurrence of sleep disorders with NDEBIDs makes an argument for bringing these together under the same wider umbrella.

### ***Conflicting definitions of NDEBIDs and varying prevalence rates***

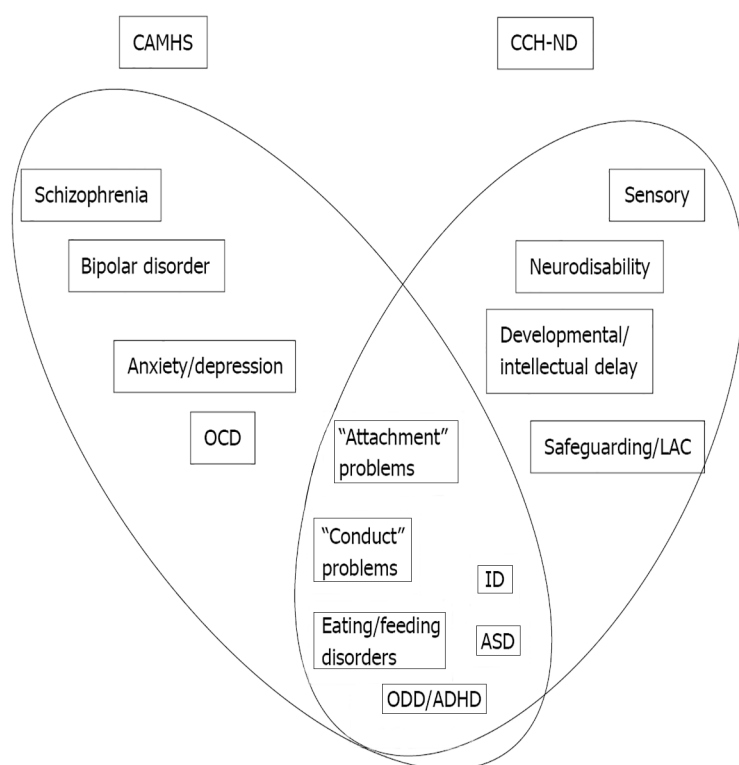
The ICD, like other classification systems, is designed to allow the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different countries and at different times[49]. Classification systems have invaluable roles in epidemiological studies, including monitoring of incidence and prevalence of diseases, and other health problems in relation to other variables. Criteria and labels for many of the NDEBIDs have changed with each revision of classification systems. This together with the lack of consensus among clinicians about the classification of the various childhood NDEBIDs, has led to widely varying estimates of disease prevalence rates, and has made universal comparison of research findings almost impossible[5]. It is therefore not surprising that a wide range of prevalence rates have been reported for different conditions (Table 1).

Recorded prevalence of childhood disabilities is an example of where diverse rates have been reported within the same country. In the United Kingdom, one study reported 7.3% of CYP aged 0-18 years (8.8% of boys and 5.8% of girls) as disabled[41] while on the other hand, Blackburn *et al*[51] reported that 6% of all children were disabled with 3%-4% having neurodevelopmental impairments in England. Furthermore, worldwide comparison is difficult to find as different countries have varying definitions for “disabilities”[41].

Multiple terms have been used to describe the “Neurodevelopmental disorders (NDD)”; these include neurodevelopmental “disorders”, “impairments” and “disabilities”. Other authors have used the term “Neurodisabilities”. It is difficult to be sure that these terminologies are used to describe the same group of disorders. For example, the following three definitions appear to be referring to the same conditions. The term ‘neurodevelopmental disorders’ applies to a group of disorders of early onset that affect both cognitive and social communicative development, are multi-factorial in origin, display important sex differences where males are more commonly affected than females, and have a chronic course with impairment generally lasting into adulthood[5]. The European Union defined “neurodevelopmental disorders” as disabilities in the functioning of the brain that affect a child’s behaviour, memory or ability to learn *e.g.*, mental retardation, dyslexia, ADHD, learning deficits and autism. In the United Kingdom, “neurodisability” has been described as a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. Their impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour[41]. Similarly, there has been little consensus among international researchers about the definition of individual “neurodevelopmental disorders”. Many authors have argued that the NDDs lack precise boundaries in their clinical definitions, epidemiology and genetics. Many symptoms are not unique to any single NDD, and several NDDs have clusters of symptoms in common[52]. Some have argued that the term NDD is unhelpful and should be abandoned[5].

### ***Traditional segregation of CCH and CAMH services despite overlapping clinical roles***

Despite the high prevalence of long-term co-occurring mental disorders in CYP with NDD and intellectual disorders[29,53,54], the involvement of psychiatric and psychological professionals, who are mostly part of CAMHS rather than paediatric services, in the provision of support for the health disorders problems comorbid with NDDs is not consistent throughout the United Kingdom and other advanced countries. Services that are designed to support these CYP often tend to be fragmented and disjointed such that the CYP have to attend multiple clinic appointments with different health-care providers and professional groups each looking at only one aspect of their complex need often without



**Figure 1** Showing a schematic representation of the overlap between some neurodevelopmental, behavioural, emotional and psychiatric disorders with an overlap between current child and adolescent mental health service and Community Child Health services. CCH-ND: Community Child Health/Neurodevelopmental Paediatrics; OCD: Obsessive compulsive disorder; CAMHS: Child and adolescent mental health service; ID: Intellectual disorder; ASD: Autism spectrum disorder; ODD: Oppositional defiant disorder; ADHD: Attention deficit hyperactivity disorder.

any coordination[9,42].

In the United Kingdom and other developed countries, NDEBID conditions are commonly managed by either CCH paediatricians or CAMH psychiatrists within multidisciplinary teams of other allied professionals[2]. The split between these services can be even more complex such that for the same diagnosis such as ASD, some younger children may be seen by CCH while older young people are seen by CAMHS[55]. Despite the natural overlap between the roles of CCH paediatricians and mental health practitioners (Figure 1), there is often very little interaction or joint-working between CCH and CAMH services in the United Kingdom, even though this collaboration is regarded as highly desirable and necessary[12].

The likelihood of CAMHS professionals working jointly with CCH paediatricians is highly variable and seems to be reducing over the years, in the face of service pressures. For example, while ADHD was originally the remit of CAMHS, CCH services have played an increasingly important role in managing this condition. Thus 63% of CCH services managed ADHD in 2016 compared to only 15% in 2006[13]. The Royal College of Paediatrics and Child Health Workforce Census 2013 revealed a decline in regular joint educational meetings between CCH and CAMHS professionals from 15.4% in 2011 to 12.8% in 2013, a reduction in ad hoc meetings with CAMHS from 42% to 26.8% and an increase from 11.7% to 15% of services that have no direct contact with their local CAMHS[56]. A recent report from the United Kingdom highlighted two CAMHS that do not provide access to children with ADHD or autism[57].

Stigma among professionals is another potential barrier to integration of services for CYPs with NDDs and co-morbid MHD. There is evidence to suggest that some health professionals have negative attitudes towards CYP affected by mental illness[58,59]. The stigmatising attitude towards CYP with mental health could also extend to stigmatisation of professionals who work in CAMHS[60] through a process known as "courtesy stigma"[61]. The implication is that if professionals working in CCH and other paediatric services have negative stigmatising attitudes towards CYP with mental health difficulties and or towards professionals working in CAMHS, they may be less likely to think favourably about integrating services for CYPs with NDDs and additional mental health needs[62].

## RECOMMENDATIONS FOR ADDRESSING CLASSIFICATION-RELATED PROBLEMS FOR NDEBID CONDITIONS

### *Value of a unified classification of mental health and NDD*

There are grounds for agreement on aspects of the scientific basis for the grouping together of neurodevelopmental and some MHD. First, clinical overlap between these disorders is high and they also behave as highly correlated traits. Thus, research that focuses on a single diagnosis (e.g., autism) should allow for testing the contribution of accompanying neurodevelopmental difficulties. Secondly, NDD share common features with some related MHD including onset early in development, tendency to show a steady course and affecting males more commonly than females. Thirdly, there is a strong genetic overlap across different neurodevelopmental problems[37]. Finally, comorbidity between neurodevelopmental and MHD is well recognized as a factor in the care of children with certain neurological diagnoses, with epilepsy the most prominent example[63], thus grouping them together could help to better enhance the study of the scientific basis and epidemiology of their co-occurrence, as well as improving clinical management.

Studies have shown that CYP with NDEBIDs are at increased risk of developing sleep disorders as well as secondary MHDs such as anxiety, depression, obsessive compulsive disorder (OCD), self-harming, suicidal behaviours, and conduct disorder in up to 50% of those affected[29,53,64,65]. The clinical and research advantages from considering NDDs together with the MHD[40] form the basis for our use of the NDEBID terminology in this paper.

Many clinicians and researchers have questioned the fundamental reason for having more than one classification system used worldwide[5]. Unifying classification systems based on empirical and scientific foundations agreed by consensus among global specialists would probably aid rapid advancement of research across all countries and regions worldwide. There is also evidence that patients and families of CYP with NDEBIDs would also prefer a more unified and integrated approach to their care. When a wide range of stakeholders including families, referrers and CAMHS professionals were requested to state their priority values, “a need for a common language for all agencies when discussing mental health” and “a holistic approach where problems are not inappropriately medicalised” were some of the regular themes found[66]. The global status of the WHO means that ICD is the system most likely to meet this aim and the most recent revision of ICD-11 has made a clear departure from the preceding versions with the new chapter heading of “Mental, Behavioural and NDD” and a sub-heading that brings together a range of conditions previously classified under various headings such as “behavioural and emotional disorders” and “pervasive developmental disorder”. This approach is based on assumption of improved clinical utility and global applicability. While this should be regarded as a welcome development, there are still arguments from some clinicians and researchers against this. For example, various conditions (from severe ASD to mild coordination disorder) contained under this grouping differ from each other such that they have little in common[5].

### *Focusing on impairments and complexities over diagnosis*

Complexity and comorbidities are common features of many NDEBIDs and pose a great challenge to clinicians. It is often the complexity of a case that leads to a need for intervention in sub-threshold disorders. Unfortunately, this problem has not been properly addressed in research. Many families, referrers and CAMHS professionals have been reported placing high values on “a holistic approach where problems are not inappropriately medicalised” and “services that take into account what is important in CYP’s lives”[66].

Research methodologies using small N studies may help to explore the value of interventions in complex cases and agreement on a shared language for sub-threshold disorders would facilitate this kind of research[67]. In this regard, DSM-5 has introduced the concepts of “clinical case formulation” and “clinical significance”. It defines clinical significance of a disorder in terms of consideration of thresholds of a person’s distress or impairment in his or her social, occupational and/or other important areas of functioning in daily life. The clinical formulation can co-exist with diagnostic classification and provides an alternative to a multiaxial system requirement, with a clinical summary of the social, psychological and biological factors that contribute to the development of a mental disorder. It allows more homogeneous subgroupings of a disorder to indicate shared features[68].

### *Need for greater care integration for CYP with NDEBIDs*

There is strong evidence that children with neurodevelopmental and intellectual disorders have three to four-fold increase in the prevalence of co-occurring mental disorders into adulthood[2,9,69]. For example, pooled prevalence for co-occurring MHD in autism is estimated at 28% [95% cumulative incidence (CI): 25-32] for ADHD; 20% (17-23) for anxiety disorders; 13% (9-17) for sleep-wake disorders; 12% (10-15) for disruptive, impulse-control, and conduct disorders; 11% (9-13) for depressive disorders; 9% (7-10) for OCD; 5% (3-6) for bipolar disorders; and 4% (3-5) for schizophrenia spectrum disorders [64]. In a Swedish community sample, 87% of children with ADHD had at least one co-morbid condition, with rates of ODD of 60%, DCD (47%), ‘reading/writing disorders’ (40%) and TD (33%), even “sub-threshold” ADHD was associated with a similar rate of co-morbid DCD[70].



Effective management of CYP with MHD and behavioural difficulties requires access to psychological therapies and sometimes, psychotropic medications, which most CCH paediatricians are not trained to use. Similarly, CAMHS teams may lack the expertise required to deal with children with sensory or motor impairments. These conditions are best seen and treated within a comprehensive integrated CCH/CAMH service with teams of specialist professionals working together to provide holistic care[9].

The need for integrated care for CYP with NDEBIDs and mental health difficulties has been recognized for many years and is a priority goal for the WHO[71]. Integrated care involves overcoming the breakdown in communication and collaboration that can arise between different parts of the system and different groups of professionals, whilst respecting necessary professional boundaries. An important feature of integrated care is moving beyond pathways for specific diseases[72,73]. System integration across borders/barriers between different sectors of the health services and other systems such as social care and education is the ideal way of preventing adverse outcomes and poor patient experience due to systemic barriers[74]. Close integration of preventive and therapeutic mental health into traditional CCH services accessible to vulnerable CYP and their families within the public care system been identified as the best way to provide them with optimal holistic care they need[75].

Since co-occurrence of NDD is the rule rather than the exception in clinical practice, grouping professional expertise, services and resources for CYP with NDEBIDs organized as part of a neurodevelopmental hub of expertise has been advocated as the optimal option for achieving holistic and comprehensive care[40]. The bio-psycho-social and ecological origins of NDEBIDs and associated mental health difficulties make it imperative that assessment and treatment of affected CYP should be multimodal, comprehensive and holistic, to capture the full range of CYP's needs in order to produce a full formulation and profile to inform their care plans.

Integrated CCH/CAMH care would provide a framework for a more joined-up assessment and treatment in a manner that is more compatible with the complex needs of CYP with NDEBIDs conditions[9,15,76]. Of course, this should not impede the independent professional activities of CAMHS and CCH where joint working is not required.

Evidence from many countries and cultures show that fear of mental health stigma can prevent CYP from seeking help[77]. The negative impact of stigma on help-seeking may be more noticeable among minority ethnic groups living in Western Europe and North America[78-80]. Provision of holistic care within integrated CCH/CAMH services could help to mitigate negative impact of mental health stigma on help-seeking behaviour among CYP with NDEBID[81,82]. Primary care settings such as routine paediatric clinic or family medicine/general practitioner have been reported to possess several desirable characteristics that make them ideal settings for providing effective mental health services to CYP. They are not associated with the stigma typical for bespoke CAMHS, they are often in a local familiar setting, with access to friendly healthcare providers[32,83,84].

It is pleasing to note that a few services across the United Kingdom are beginning to pilot or implement holistic multi-disciplinary clinical pathways for all NDEBID, rather than restricted pathways for individual conditions[42].

## CONCLUSION

Recent progress made in the current classification of NDEBIDs has been described. Previous attempts at classifying NDEBID conditions have been fraught with difficulties as there are many possible constructs that need to be taken into consideration. Classification based on causality is particularly problematic because the aetiology of these disorders is not only multi-causal but also incompletely understood[5]. The ICD-11 (and less so with DSM-5) have taken the lead in following a pragmatic approach where the NDEBID conditions are grouped together based on their similar neurobiological phenotypes, until further advances in neurosciences permit more categorical classifications based on aetiologies.

In many countries worldwide, one or more of the NDEBIDs would be assessed and treated by CCH/paediatric services while others and any associated mental health difficulties may be addressed by CAMHS separately and often in a disjointed fashion[9]. Diagnosis of NDEBIDs based on subjective assessment of behaviour by clinicians and carers is prone to biases but reliable standardized instruments can support diagnosis. Recent advances such as computerized CPT tests have potential in the assessment of some NDEBIDs.

Despite the concerns of some authors, it might be reasonable to suggest that the latest WHO classification (ICD-11) could form the basis for a shared understanding acceptable to both the CCH and CAMHS. A more unified approach to classification offers a basis for an integrated care approach, with more consistent collaboration between CCH and CAMH services to address stigma and ensure more holistic care for CYP with NDEBIDs. We note the case for bringing sleep disorders in CYP under the same wider umbrella as the NDEBIDs. We also argue for simultaneous interventions for the total profile of difficulties that accompany the primary diagnosis, even if these do not reach the required threshold for a so-called comorbid diagnosis.



## FOOTNOTES

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