

## REVIEW

# Neurodevelopmental disorders and incontinence in children and adolescents: Attention-deficit/hyperactivity disorder, autism spectrum disorder, and intellectual disability—A consensus document of the International Children's Continence Society

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## Abstract

**Aims:** Neurodevelopmental disorders (NDs) are incapacitating disorders, which begin early in life, are mainly caused by genetic and neurobiological factors, and show a tendency to persist. They are associated with higher rates of incontinence in children and adolescents, including nocturnal enuresis, daytime urinary incontinence, fecal incontinence, and constipation. Without diagnosis and treatment, they will interfere with incontinence treatment leading to less favorable outcomes. The aim of this International Children's Continence Society (ICCS) document is to provide an overview of the three most important NDs, that is, attention-deficit/hyperactivity disorder, autism spectrum disorder (ASD), and intellectual disability (ID).

**Methods:** This consensus paper was commissioned by the ICCS. A selective, nonsystematic review was performed. Guidelines, reviews, and selected studies were included. The recommendations are consensus-based.

**Abbreviations:** ADHD, attention-deficit/hyperactivity disorder; AMPH, amphetamines; ASD, autism spectrum disorder; CBT, cognitive-behavioral therapy; CD, conduct disorder; DUI, daytime urinary incontinence; FI, fecal incontinence; ICCS, International Children's Continence Society; ID, intellectual disability; IQ, intelligence quotient; MPH, methylphenidate; ND, neurodevelopmental disorder; NE, nocturnal enuresis; ODD, oppositional defiant disorder.

**Results:** ADHD is the most common ND with special relevance in clinical practice. ASD and ID are less common, but more severe disorders than ADHD. Basic principles of the assessment and treatment of NDs are provided. Incontinence is common among patients with NDs. Specific modifications and practical approaches in the treatment of incontinence in children with NDs are outlined.

**Conclusions:** Incontinence in children and adolescents with NDs is common. Effective treatment of incontinence should be adapted and modified to the specific needs of patients with NDs. A multiprofessional approach is recommended.

#### KEYWORDS

adolescents, attention-deficit/hyperactivity disorder, autism spectrum disorder, children, daytime urinary incontinence, fecal incontinence, intellectual disability, neurodevelopmental disorders, nocturnal enuresis, urotherapy

## 1 | INTRODUCTION

Neurodevelopmental disorders (NDs) are conditions, which begin early in life and are characterized by a wide variety of impairing developmental deficits.<sup>1</sup> The etiology of NDs encompasses mainly genetic and neurobiological factors and they show a tendency to persist, that is, they are chronic disorders.

According to the *DSM-5* classification system, the following are considered as NDs: intellectual disability (ID), communication disorders (encompassing language disorder, speech sound disorder, childhood-onset fluency disorder [stuttering]), social (pragmatic) communication disorder, autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), specific learning disorder (such as dyslexia and dyscalculia) and motor disorders (including developmental coordination disorder), stereotypic movement disorder, and tic disorders (e.g., Tourette disorder).<sup>1</sup>

NDs often occur in association with other NDs (such as ASD and ADHD), but also a wide range of other comorbid conditions. Nocturnal enuresis (NE), daytime urinary incontinence (DUI), fecal incontinence (FI), as defined by the International Children's Continence Society (ICCS), and constipation are more common in children with NDs—and vice versa.<sup>2–5</sup> NDs can present additional challenges in incontinence treatment. Untreated, NDs will persist, will interfere with incontinence treatment (urotherapy), and will lead to less optimal adherence and outcome results.

So far, research has focused on the three major groups of NDs with especially high rates of NE, DUI, and FI, that is, ADHD, ASD, and ID.<sup>3–5</sup> Due to their relevance in clinical care, this ICCS document will focus on these three NDs. The aim of this paper is to provide professionals in the incontinence field with practical information to be able to

recognize and deal with these common comorbid disorders among children with incontinence. Toilet training in NDs is outside the scope of this document, although the specific problems and helpful strategies tabulated below may prove helpful.

## 2 | METHODS

This consensus document was commissioned by the ICCS and its aim is to give an overview of the three most important NDs and their relevance for incontinence treatment. This is a selective, nonsystematic, simple review with practical recommendations for the assessment and treatment of childhood incontinence in NDs. Due to the constraints of the journal, we did not conduct a systematic search but selected relevant reviews, guidelines, and important papers on the topic based on the suggestions of all authors.

As a consensus paper, it reflects the current recommendations of the ICCS. All members of the ICCS were given the opportunity to provide input through the homepage of the ICCS. As no major controversies exist on the importance of NDs regarding incontinence, the aim was to provide a current consensus-based overview for the clinical care of children and adolescents.

## 3 | RESULTS

### 3.1 | ADHD

ADHD is defined by persistent symptoms of inattention and/or hyperactivity-impulsivity with impairment for the affected

children. Both symptom complexes are clearly listed in the *DSM-5*. Of the nine items of inattention and nine of hyperactivity-impulsivity, at least six are required for a diagnosis of ADHD, respectively. Examples for items of inattention are “often has difficulty sustaining attention to tasks or play activities, has difficulty remaining focused during lectures, conversations, or lengthy reading”; of hyperactivity “often fidgets with hands or feet or squirms in seat”; and of impulsivity “often has difficulty waiting for his or her turn, e.g., while waiting in line.” Clinicians are referred to the *DSM-5* for a full list of all items.<sup>1</sup>

A duration of 6 months, an onset before the age of 12 years, the presence in two or more settings, incapacitation in social, academic, or occupational functioning, and the exclusion of other mental disorders are required for a diagnosis. Three presentations (subtypes) can be differentiated: combined (inattention, hyperactivity, impulsivity), predominantly inattentive (only inattention), and predominantly hyperactive-impulsive (mainly hyperactivity and impulsivity). Mild, moderate, and severe degrees of current severity are outlined and should be specified.<sup>1</sup>

The worldwide prevalence of ADHD is 5% in children and 2.5% in adults. More boys than girls are affected (2–3:1).<sup>6</sup> The heritability is high (0.7–0.8), that is, 70%–80% of the etiological variance can be explained by genetic factors.<sup>7</sup> ADHD is a polygenic disorder and several genes have been identified, including the dopamine-4 receptor, dopamine transporter, and other genes.<sup>8</sup> ADHD can be diagnosed from the age of 3 years onwards.<sup>9</sup> For young children (age 0–5 years), the *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood (DC:0–5)* is more specific and sensitive.<sup>9</sup> ADHD is a chronic disorder: two-thirds of adolescents and one-third of adults with a childhood diagnosis are still affected.<sup>10,11</sup> ADHD carries long-term developmental risks for substance abuse and other disorders.<sup>12–14</sup>

The rate of comorbid disorders in ADHD is high and two-thirds of children are affected by at least one concomitant disorder.<sup>12</sup> Typical disorders include oppositional defiant (ODD), conduct (CD), depressive and anxiety disorders, specific developmental disorders like speech disorders, ASD, and tic disorders.<sup>12,15</sup>

### 3.2 | Incontinence in ADHD

The rate of incontinence is increased in children with ADHD.<sup>4</sup> According to different studies, approximately 20%–30% of children with ADHD have NE.<sup>4</sup> Less data is available on DUI and FI in children with ADHD.<sup>4</sup> Far more clinical and population-based studies have analyzed the rates of ADHD among children with incontinence.<sup>4</sup> For example, the rate of ADHD among children

with NE (17.6%), with DUI (24.8%), and with FI (13.2%) was significantly increased in 7-year-old children in a large population-based study, as well as in other studies.<sup>16–18</sup> Although the heritability is high for ADHD as well as NE, the limited genetic studies on NE and ADHD do not explain the high co-occurrence of both disorders. Furthermore, functional deficits of the CNS, environmental, psychosocial, or epigenetic factors are discussed as common neurological factors.<sup>4</sup> Specific brain regions such as the anterior cingulate gyrus and the dorsal anterior midcingulate cortex are involved in both ADHD and incontinence.<sup>19</sup>

The presence of ADHD has a negative influence on incontinence treatment: The compliance in children with ADHD is much lower and treatment outcomes are worse.<sup>4,20</sup> Therefore, the identification and treatment of ADHD are necessary for children with incontinence.

### 3.3 | Assessment and treatment of ADHD

Several ADHD guidelines have been issued in many countries, including the American Academy of Pediatrics guidelines for the United States of America, the National Institute for Health and Care Excellence guidelines for the United Kingdom, and the Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften guidelines for Germany.<sup>15,21,22</sup>

The diagnosis of ADHD is based on a clinical mental health assessment by an appropriately trained professional, including history, mental state examination, questionnaires, intelligence, and other tests, as well as physical examination.<sup>21</sup> Electrocardiogram (ECG), electroencephalogram, and laboratory tests are not mandatory, but can be indicated in certain cases.<sup>21,22</sup> For example, with pre-existing cardiac disease in the child or family, ECG and further cardiology examinations may be indicated before initiating medication, particularly as there is potential for drug interaction, for example, methylphenidate (MPH) and imipramine. Imaging or genetic assessment is usually not indicated on a routine basis.

Counseling and provision of information for the child, parents, and, if indicated, teachers should be offered when a diagnosis of ADHD has been confirmed.<sup>21</sup> In mild cases and in preschool children, psychosocial interventions (e.g., psychoeducation and parental training) should be conducted first and pharmacotherapy only if needed.<sup>15,22</sup> In moderate cases, psychosocial interventions can be combined with pharmacotherapy. In severe cases, an intensive psychosocial and pharmacotherapeutic approach is recommended.<sup>22</sup> Of all psychosocial

interventions, cognitive behavioral therapy (CBT) is the most effective, which encompasses a wide range of different techniques.<sup>21</sup> Of course, all comorbid disorders should be treated in addition to ADHD.<sup>15</sup>

Neurofeedback, omega-3 fatty acids, diets, other forms of psychotherapy, occupational therapy are not, or only minimally, effective for core ADHD symptoms.<sup>15,22</sup> In contrast, stimulant medication is highly effective with effect sizes of 0.4–0.8 in preschool and 0.6–1.2 in school children. First-line medication is MPH, as a short- (3–4 h) or, preferably, long-acting (6–10 h) formulation. The main effect of MPH is to block presynaptic dopamine and noradrenalin reuptake, thereby increasing dopamine and noradrenalin concentration in the synaptic cleft of the prefrontal cortex.<sup>22,23</sup>

There are no absolute contraindications to MPH. Relative contraindications are untreated epilepsy, severe tic disorders, substance abuse, and cardiac disease. The medication should be tapered up slowly in one dose in the morning (long-acting MPH) or two doses in the morning and at mid-day (short-acting MPH).

Seventy percent of children respond to MPH. Primary effects are a reduction of hyperactivity, an increased attention span, and other cognitive effects such as improved short-term memory. Secondary effects are improvements in parent–child interaction, peer relationships, and reduction of aggressive and impulsive behavior. Side effects include sleeping disorders, reduced appetite, abdominal pain, irritability, depressed mood, increased heart rate, increased blood pressure, and in subgroups of children, reduced growth. Regular monitoring of weight, length, blood pressure, and heart rate is recommended.<sup>22</sup>

For those who do not respond or show marked side-effects to MPH, second-line medications are dexamphetamine or lys-dexamphetamine.<sup>21</sup> 90% of children respond to either MPH or amphetamines (AMPH). AMPHs have similar effects and side-effects as MPH, but due to a different mode of action (presynaptic secretion of dopamine), different groups of children respond to MPH or AMPH. The dosage of AMPH is usually lower than that of MPH.<sup>21,22</sup>

Prescription of stimulants is highly regulated in many countries. The advantage of stimulants is that in addition to being highly effective, they can be prescribed variably due to their short length of action (e.g., only during school days, etc.).

If children do not respond to either MPH or AMPH, the third-line medication is atomoxetine, a selective noradrenalin-reuptake inhibitor.<sup>21</sup> The main side-effects are gastrointestinal. Atomoxetine has to be taken every day and tapered up with one dose in the morning and with a 24-h effect. The effects become apparent after 4–6 weeks.

Finally, the fourth-line medication is guanfacine, an alpha-adrenergic receptor-agonist.<sup>21</sup> The medication is tapered up in weekly steps with one dose in the morning, which provides a 24-h effect. The main side effects are low blood pressure and decreased heart rate.

If possible, only one substance should be prescribed at a time (monotherapy).<sup>21</sup> Other medications such as antipsychotics or antidepressants are not effective for the treatment of core ADHD symptoms but can be indicated if comorbid disorders (e.g., severe conduct disorder or ASD with disruptive symptoms) are present in the affected child. The basic principles of ADHD are summarized in Table 1.

### 3.4 | ASD

ASD is a severe ND with incapacitating symptoms in social interaction and communication or stereotyped-repetitive behaviors.<sup>1</sup> Items of these two domains are specified in the *DSM-5* classification system but are not comprehensive. According to the *DSM-5*, examples for deficits in social communication and interaction are “deficits in social–emotional reciprocity, limited eye contact, reduced sharing of interests, emotions or affect,” which have to be present across multiple contexts. Two or more items of restrictive, repetitive patterns of behavior are required, such as “stereotyped or repetitive motor movements or speech, inflexible adherence to routines, or hyper- or hypoactivity to sensory input.” Onset in early development, impairment, and exclusion of other disorders, which would explain the symptoms better, are also required for a diagnosis. Clinicians are referred to the *DSM-5* for further details.<sup>1</sup>

The previous categorical division of autism into childhood autism, atypical autism, and Asperger's syndrome has been dropped in favor of a spectrum disorder in *DSM-5*, ranging from mild to severe forms with varying comorbid conditions. According to *DSM-5*, one should specify if ASD is associated with comorbid ID, language impairment, other neurodevelopmental, mental, or behavioral disorders, a genetic syndrome, or an environmental factor.<sup>1</sup> The severity can vary from “requiring support” to “requiring very substantial support,” that is, in three major levels.

ASD can be recognized from the second year of life onwards. For young children, the *DC:0–5* criteria are more sensitive.<sup>9</sup> The prevalence of ASD is approximately 1%. Five times more boys are affected than girls.<sup>24</sup> The heritability for ASD lies between 64% and 91% and environmental and epigenetic factors increase the risk of ASD.<sup>1,24,25</sup> 15% of persons with ASD have a genetic syndrome (e.g., Fragile-X-syndrome, tuberous sclerosis).

**TABLE 1** ADHD—Practical summary for clinicians in the incontinence field (consensus statement based on current guidelines)

ADHD is the most common ND.
Comorbidity rates of NE, DUI, and FI are increased in children with ADHD—and vice versa.
Untreated ADHD can interfere with incontinence treatment and lead to worse outcomes.
The diagnosis of ADHD is based on a professional clinical assessment and should adhere to <i>DSM-5</i> criteria.
In young children, <i>DC:0-5</i> criteria are more specific.
Comorbid disorders of ADHD need to be diagnosed and assessed.
ADHD is a chronic disease with long-term developmental risks.
Counseling should be offered in every case.
The type of intervention is tailored to age, the level of severity, and the degree of incapacitation.
In mild cases and preschool children: first psychosocial interventions; if not sufficient, medication.
In moderate cases: both psychosocial interventions and medication.
In severe cases: primarily medication, accompanied by psychosocial interventions.
CBT is the most effective psychosocial intervention.
Medication is highly effective.
Methylphenidate is the first-line medication.
Amphetamines are second-line medications.
Atomoxetine is the third-line medication.
Guanfacine is the fourth-line medication.
Change medication only if not effective or if marked side effects are present.
The sequence of medication can vary from one country to the next depending on the availability, affordability of the medication, and the recommendations of national guidelines.
All patients with medication should be followed regularly and side effects should be monitored.
Urotherapy needs to be adjusted to the needs of children with ADHD.

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; CBT, cognitive-behavioral therapy; DC:0-5, Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood; DUI, daytime urinary incontinence; FI, fecal incontinence; ND, neurodevelopmental disorders; NE, nocturnal enuresis.

The remaining 85% of nonsyndromic forms of ASD are oligo- or polygenic. As an ND, ASD is accompanied by specific anomalies in brain anatomy, functioning, and brain connectivity.<sup>26</sup> Seventy percent of children and adolescents have a comorbid psychiatric disorder (e.g.,

ADHD, developmental disorders, anxiety, depression, sleep disorders).<sup>1,21,24</sup> Comorbid psychiatric disorders continue to be very common throughout the lifespan of individuals with ASD, especially anxiety and depression.<sup>27</sup> In addition, approximately half of children with ASD are affected by ID.<sup>28</sup>

### 3.5 | Incontinence in ASD

The rates of NE are higher in ASD than in the normal population ranging from 2% up to 90% (median 22.6%) according to a systematic review.<sup>5</sup> DUI is also more prevalent in ASD than in typically developing persons, with rates of 13.3%–55% in selected cohorts.<sup>5</sup> NE and DUI can represent side effects of medication such as risperidone or other antipsychotics. The range of FI varies from 2% to 70.6% (median 12.8%).<sup>5</sup> Conversely, the rates of ASD are increased in children with incontinence. However, most studies are characterized by methodological limitations and definitional discrepancies.<sup>5</sup> Children with ASD have a special risk for constipation and other functional gastrointestinal disorders.<sup>29</sup> Successful therapy outcome is lower than in the typically developing population.<sup>30</sup> The treatment of incontinence in children with ASD is more time-consuming and needs a more structured and intensive behavioral approach.<sup>2,31,32</sup>

### 3.6 | Assessment and treatment of ASD

The diagnosis of ASD requires a full mental health, as well as a pediatric assessment.<sup>28,32,33</sup> The gold standard required for diagnosis includes the Autism Diagnostic Interview—Revised parent interview, the Autism Diagnostic Observation Scale, and an intelligence or developmental test.<sup>28</sup> Questionnaires and other specific instruments can be required. All comorbid disorders should be diagnosed.<sup>28</sup> Genetic assessment is recommended when indicated. Imaging and further assessments (ENT, ophthalmology, neurology, etc.) are often required when specific symptoms are present.

The treatment of ASD includes parent training and counseling, as well as CBT.<sup>34</sup> All comorbid disorders should be addressed separately. If indicated, speech-, occupational-, and physiotherapy can be useful. Children and adolescents with ASD often require special education, assistance from social services, and specific types of treatment developed for ASD, such as the Treatment and Education of Autistic and related Communication handicapped Children or Applied Behavior Analysis programs and their variants. These should focus on increasing social skills and everyday competencies, and

fostering play and interactive strengths. Repetitive and stereotypic behavior should be restricted.

No specific medication is available for ASD.<sup>34</sup> However, stimulants can be indicated and are very useful in comorbid ADHD, antiepileptic medication for seizures, antipsychotics (such as aripiprazole or risperidone) for aggressive and disruptive behavior, antidepressants for depression, anxiety, and obsessive-compulsive disorder, and melatonin for sleep disorders.<sup>34</sup>

In clinical practice, ASD is usually a much more severe disorder than ADHD, which can impact the child, siblings, and parents. In view of the many associated problems, incontinence is often not adequately addressed, diagnosed, and treated, although achieving continence will reduce stress in many families. Principles for the clinical care of patients with ASD are summarized in Table 2.

### 3.7 | ID

According to *DSM-5*, ID is defined by deficits in intellectual and adaptive functioning, which have their onset during the developmental period. Intellectual functioning comprises reasoning, problem-solving, planning, abstract thinking, and so forth. Adaptive functioning refers to how well a person meets community standards in conceptual, social, and practical domains.<sup>1</sup>

ID is characterized by an intelligence quotient (IQ) < 70. Four levels of severity can be differentiated: mild ID (IQ 50–69), moderate (IQ 35–49), severe (IQ 20–34), and profound (IQ < 20) ID. Of all types of ID, mild ID is the most common (80%), followed by moderate (12%), severe (7%), and profound (less than 1%) (REF).

The prevalence of ID is around 1%–3.4%.<sup>35</sup> Males are overrepresented (1.5:1). ID is a heterogeneous condition of multiple causes, most of which originate prenatally. A perinatal or postnatal etiology is the exception. Prenatal causes included teratogenic effects (such as alcohol and medication), infections (such as rubella), and other environmental factors (obstetric complications). The most important causes are genetic, which account for 25% of cases in persons with mild ID and in even for 43%–48% in persons with severe ID.<sup>36,37</sup> A wide variety of genetic syndromes can be associated with ID. With newer genetic techniques such as micro-arrays and copy number variants, genetic causes can be identified in most cases of ID, especially in moderate, severe, and profound ID.<sup>36</sup> Idiopathic ID (no definite cause) is due to a polygenic multifactorial transmission and mainly affects individuals with mild ID.<sup>36,38</sup>

**TABLE 2** ASD—Practical summary for clinicians in the incontinence field (consensus statement based on current guidelines)

ASD is less common, but overall a more severe ND than ADHD.

ASD can be a life-long, chronic and incapacitating disorder.

Comorbid disorders are common, especially ADHD.

The degree of severity needs to be specified, as many children are affected by ID.

The rate of NE, DUI but especially FI and other gastrointestinal disorders is higher in children with ASD.

Children with ASD can present major challenges during incontinence training.

The diagnosis of ASD is based on specific professional assessments and should follow *DSM-5* criteria.

For young children, the *DC:0-5* criteria are more sensitive and specific.

The gold standard includes the ADI-R parent interview, the ADOS observation instrument, a developmental or intelligence test.

Genetic testing is required in most cases to identify syndromic cases.

Counseling is recommended in every case.

Specific programs for the treatment of ASD are most effective.

CBT is the first-line approach for psychotherapy.

Additional treatment can be indicated, such as speech-, occupational-, or physiotherapy.

Suitable special education services are important for many children with ASD.

Medication is not effective for the core symptoms of ASD but can be indicated for comorbid disorders such as ADHD, disruptive, conduct, depressive, and anxiety disorders.

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; ADI-R, Autism Diagnostic Interview—Revised; ADOS, Autism Diagnostic Observation Scale; ASD, autism spectrum disorder; CBT, cognitive-behavioral therapy; DC:0-5, Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood; ID, intellectual disability.

The identification of specific syndromes is not just important for genetic counseling, but also for planning treatment and intervention for the children, due to their behavioral phenotype of comorbid psychological symptoms and disorders. Behavioral phenotype is defined as a pattern of behavioral, social, language, and cognitive symptoms associated with a genetic disorder.<sup>39</sup> Comorbid psychiatric disorders are common in individuals with ID, increasing from a rate of 33% in mild ID to 42% in severe ID.<sup>38</sup>

### 3.8 | Incontinence in ID

A comparable inverse relationship with IQ is typical for the rate of incontinence: the lower the IQ (i.e., the more severe the ID), the higher the rate of incontinence. In a representative population-based study of 7-year-old children, 38.1% had NE, 39% DUI, and 30.5% FI.<sup>40</sup> In addition, these rates remained high even at the age of 20 years. Most children and adolescents with ID have the same type of nonorganic incontinence as typically developing individuals. Children with ID have more incomplete bladder emptying, interrupted uroflows, and smaller bladder capacities than typically developing children.<sup>41</sup>

In the meantime, studies on incontinence have been conducted in a wide spectrum of syndromes: For mild ID, in Down, Williams, Prader-Willi, and Noonan syndromes and others; for moderate ID, in Fragile-X and for severe or profound ID in Angelman, Mowat-Wilson, Phelan-McDermid and Rett syndromes (see Table 3).

**TABLE 3** ID—Practical summary for clinicians in the incontinence field (consensus statement based on current guidelines)

ID is a heterogeneous condition.
ID cannot be diagnosed clinically.
ID requires psychological testing with an intelligence test. If testing is not possible, an evaluation with adaptive scales is an alternative.
Different levels of severity can be differentiated from mild to profound ID.
A full pediatric and genetic assessment is needed to identify associated syndromes and the somatic phenotype.
Mental health assessment is needed to identify comorbid psychological disorders.
Psychological comorbidities increase with the severity of ID.
CBT can be indicated for comorbid disorders.
Medication can be indicated for comorbid disorders.
Typical medication would be methylphenidate for ADHD, antipsychotics for disruptive behavior, antidepressants for anxiety or depression, and melatonin for sleep-onset disorders.
Individuals need special education and other social services.
Involvement of parents and caregivers is needed.
In planning interventions, IQ-level, the behavioral phenotype and comorbid disorders should be taken into consideration.

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; CBT, cognitive-behavioral therapy; ID, intellectual disability; IQ, intelligence quotient.

Again, the rate of incontinence increases in these syndromes with the severity of ID. However, in some syndromes, the rates and types of incontinence are influenced by specific aspects of the somatic and behavioral phenotype. For example, the rate of incontinence in Angelman syndrome is associated with epilepsy and in Rett syndrome possibly with motor incapacitation, scoliosis, urinary tract infections, constipation, behavioral phenotype, and breathing problems.<sup>42,43</sup> Other important contributing factors to incontinence in children and adolescents with ID are the use of diapers for micturition and defecation, lack of toileting skills, and insufficient fluid intake.<sup>44</sup> Some syndromes carry a higher risk for anomalies of the urogenital tract (as in Williams syndrome), while others have higher rates of gastrointestinal disorders (such as in Mowat-Wilson syndrome) and some both (Down syndrome).<sup>45,46</sup>

### 3.9 | Assessment and treatment of ID

ID cannot be diagnosed clinically. The level of ID requires a standardized intelligence or developmental test or, if testing is not possible, assessment with scales for adaptive functioning (e.g., Vineland Scales).<sup>47</sup> A mental health assessment is recommended to identify comorbid behavioral disorders. The physical assessment of ID includes a careful personal and family history with pedigree, pediatric, neurologic, and dysmorphological examination, chromosome, molecular, imaging, and other assessment, as indicated.<sup>48</sup>

ID cannot be cured. Persons with ID require special education and other social services. Speech-, occupational-, and physiotherapy are often required. Involvement of parents and caregivers is needed on a long-term basis. CBT, as well as medication, can be indicated for comorbid behavioral disorders. Typical medication would be MPH for ADHD, antipsychotics for disruptive behavior, antidepressants for anxiety or depression, and melatonin for sleep-onset disorders. Interventions should take the specific behavioral phenotype into account. Basic clinical principles are summarized in Table 4.

### 3.10 | Practical implications for the treatment of incontinence

The most important first step is a detailed and specific diagnosis of the type of incontinence, the type of ND and associated disorders. Treatment of the ND or psychosocial support services should have been implemented or should start before or at the same time as treatment of incontinence.

**TABLE 4** Selected syndromes of ID and associated incontinence prevalence

Syndromes	n	Ave age (range) (years)	ID level	NE (%)	DUI (%)	FI (%)	Reference
Noonan	29	15.2 (5–48)	Mild	16.0	13.8	7.4	[49]
Williams 7q11del	231	19.4 (4.1–59.9)	Mild	17.8	5.9	7.6	[45]
Prader–Willi	118	20.5 (5–45)	Mild	13.6	3.8	3.3	[49,50]
Trisomy 21/Downs	317	19.2 (4–51)	Moderate	17.2	15.9	14.2	[51]
Fragile-X	22	11.1	Moderate–severe	45.5	36.4	31.8	[52,53]
Angelman	153	15.1 (4–31)	Severe	81.0	61.4	53.9	[42]
Mowat–Wilson	47	13.0 (4–33)	Severe	97.7	76.2	81.4	[46]
Rett	63	19.34 (5–47)	Severe	98.4	96.8	57–72	[42]

Abbreviations: ID, intellectual disability; FI, fecal incontinence; NE, nocturnal enuresis.

**TABLE 5** Specific attention-deficit/hyperactivity disorder (ADHD) problems regarding incontinence and helpful strategies (based on consensus, clinical experience, and selected studies)

Problems in ADHD	Helpful strategies
<p><b>Attention deficit (inability to concentrate or focus for a long period of time):</b></p> <p>Lower response to bladder sensation</p> <p>Distracted on the way to the bathroom</p> <p>Problems:</p> <p>Adhering to urotherapy</p> <p>Remembering drinking or toileting programs</p> <p>Remembering to void before sleep</p> <p>Remembering to take medication</p>	<p>Shorter training time (e.g., in urotherapy)</p> <p>Smaller units of information</p> <p>Smaller sequential steps of intervention (e.g., first implementation of regular fluid intake, then regular voiding, etc.)</p> <p>Use visual timetables and charts to create structure.</p> <p>Use timer watches (for voiding/drinking)</p> <p>Create predictability with a “countdown warning” before changing activities.</p> <p>Increase parental support.</p> <p>Reward for cooperation (praise, tokens, rewards, other positive reinforcers, etc.).</p>
<p><b>Hyperactivity (increased motor activity and difficulties with keeping still):</b></p> <p>Bowel toileting programs: child cannot sit still for longer periods of time on the toilet</p> <p>Urotherapy: Child cannot sit still to learn about bladder/bowel function</p>	<p>Include interactive games in educational setting</p> <p>Learning with the use of drawings and other hands-on materials.</p> <p>Provide positive feedback for all desired behaviors.</p> <p>Reward for sitting on the toilet for an adequate time.</p> <p>Increase the amount of time for sitting on the toilet (e.g., first week 5 min, second week 10 min).</p> <p>Use of a timer or other visual aids for timed toilet sitting.</p> <p>Include motivational input during sitting times (e.g., video games).</p>
<p><b>Impulsivity (inability to think before acting):</b></p> <p>Problems:</p> <p>Having a drink and forgetting to stick to fluid restriction rules when taking desmopressin</p> <p>Forgetting to go to the toilet at set intervals because something more interesting is happening (play, television, video games) or quick toilet turn-around time</p>	<p>Introduce rules and reward adherence</p> <p>Increase parental or teacher surveillance/supervision (e.g. medication).</p> <p>Create a “stop signal” to remind the child to do something.</p>
<p><b>Accompanying oppositional behaviors:</b></p> <p>Refusal to comply with urotherapy</p> <p>Refusal to listen to parents when sent to toilet</p> <p>Postponement of voiding (while playing, watching TV)</p> <p>Cheating (e.g., hiding soiled underwear)</p> <p>Aggressive behavior (shouting, kicking) when parents ask them to do something (go to toilet, drink, etc.)</p>	<p>Include smartphones, watches, and other timers to remind the child to go to the toilet.</p> <p>Create comprehensible, measurable, and objectifiable rules to avoid discussions</p> <p>Reward and praise the child when complying</p> <p>Selective ignoring of minor negative behavior (e.g., shouting) and reinforcement positive behavior.</p> <p>Avoid discussions, give constructive advice</p> <p>Give positive feedback, for example, before going to bed (“What went well today?”).</p>



**TABLE 6** Specific problems and helpful strategies regarding incontinence in autism spectrum disorder (ASD) (based on consensus, clinical experience, and selected studies)

Problems in ASD	Helpful strategy:
<p><b>Deficits in social communication interaction:</b> Child fails to communicate to a parent/caregiver of their need to void or defecate and, thus, does not receive support</p>	<p>Use structured visual timetables, incorporating toilet times. Hang chart in the toilet room with the steps of toileting in pictures and consistent use of signs or terms for the toilet and toileting Introduce these as early as possible so that it becomes part of the child's daily routine. Prevent constipation by early and rigorous bowel management. Insist that even boys should sit on the toilet so that micturition and defecation can occur simultaneously. Standing may encourage withholding for bowel emptying.</p>
<p><b>Deficits in social-emotional reciprocity:</b> Child may not understand privacy and dignity issues associated with toileting. Child may void/defecate in socially unacceptable places or may not realize the significance of incontinence. Child may have difficulty understanding reasons for voiding before sleep or for timed voiding due to their autistic concrete/rigid thinking, for example, "I only wee if I feel the need."</p>	<p>Use the toilet environment for all activities associated with excretion (storing and changing diapers, cleaning, wiping, potty use, etc.) rather than a bedroom or social areas such as the family living room so the child learns the association of voiding/defecation activity with the toilet. Use positive feedback systems to enhance micturition, such as musical potties and so forth. Use spinning ping pong balls once the child is standing to reduce spillage, as long as it does not encourage interrupting micturition. Use specific, autistic restricted interest of the child to encourage time spent on the toilet and to create a positive association with the toilet, as long as it is not distracting.</p>
<p><b>Restricted repetitive behaviors:</b> Some children void repetitively as part of these restricted, repetitive behaviors and this may be mistaken for an overactive bladder.</p>	<p>Careful history and observation distinguish between restricted and repetitive behaviors. Reinforce first void, not the following voids Offer alternative games/activities that are interesting to avoid repetitions.</p>
<p><b>Restricted diet:</b> Selective food intake and low fiber content may contribute to constipation. Administration of medication can be very difficult, for example, Macrogol PEG3500 with electrolytes is often refused, even when added to fluids</p>	<p>Introduce new foods slowly but steadily. Reinforce trying out new food positively. Offer food in the way the child accepts it (e.g., in the beginning, mashed, pureed, and mixed into food that is accepted). Try out which fluid is accepted best with laxatives (water can be mixed with juice, lemonade, etc.). Try alternative laxatives.</p>
<p><b>Sensory issues:</b> The sensation of defecation may be so distressing that it results in withholding stool and retentive constipation. Some children like the consistency or smell of stool and will play with it. Likewise, the sensation of frequent or voluntarily interrupted micturition may be enjoyable. The "girdle" effect of absorbent diapers, as well as the sensation of warmth during micturition into a diaper, may be a positive sensation. The environment of the toilet room, including bright lighting and walls, sound effects (echo, flush, and hand dryers), the sensation of a cold toilet seat, and the feeling of splashing water can be aversive sensations for some autistic children.</p>	<p>Change the toilet environment to take into account the child's sensory aversions, together with appropriately supported seating and foot support. A large pillow behind the back of the child can be comforting. If the child uses a potty, this should be in the toilet with visual reinforcement of the urine being poured into the toilet. Use different clothing to make toileting easier, such as using elasticated pants. Use of lycra shorts to create a "girdle"-type effect directly rather than by the diaper. Teach children appropriate handling of stool (in case of smearing or playing). Children can help with cleaning up and flushing the toilet. Playing with mud, wet sand, modeling clay, and so forth, can be offered to those children as alternatives to reduce playing with feces. Assessment of aversive objects and use creative ways to reduce child's apprehensions (e.g., use warm toilet seat, put toilet paper into the toilet to avoid hearing water splashing). Use of an automated toileting system.</p>
<p><b>Motor issues:</b> Many children with ASD have developmental coordination disorder and find motor tasks difficult, such as managing clothing during toileting, remembering the correct sequence or order of things, wiping their bottom clean, and washing hands.</p>	<p>Help with visual clues (pictures of all steps of a procedure). Use self-help clothing, seat adjustments, special seats, stools, and armrests can be necessary. Backward-chaining: a technique whereby the child learns the last step in a series of tasks and progressively works backward to give a sense of completion</p>

**TABLE 7** Typical problems and helpful strategies regarding incontinence in the individuals with intellectual disability (ID) (based on consensus, clinical experience, and selected studies)

Problems in ID:	Helpful strategies:
<p><b>Deficits in intellectual functioning:</b>            Children have problems linking the sense of a full bladder/bowel to voiding/defecating and going to the bathroom. Learning from experience can be difficult: If toileting was successful once, it does not mean that it will be repeated or shown in other contexts (lack of generalization).            Difficulties in learning practical skills: Children do not understand toileting procedures and have problems performing them on their own.            Difficulties with problem-solving: Children need more help with soiling/wetting accidents.            Difficulties with planning: Regular voiding times cannot be planned in advance.</p>	<p>Teach the child to sit on the toilet at times when voiding/defecating is probable (e.g., after mealtimes, every 1–2 h for voiding), and reinforce accidental emptying in the toilet.            Be a role model, let children watch how parents use the bathroom, use puppets to show how it works, train in different locations (at home, at school, etc.)            Start sitting on the potty/toilet as an everyday exercise.            Praise/reward for sitting with favorite food, favorite toy, and so forth.            Use visual clues (pictures, etc.) in the bathroom or verbal prompts.            Reinforce the first step (wiping bottom with toilet paper) and train until the child can perform this without problems, then include the next step (flushing the toilet) and reinforce after both steps and so forth (chaining, shaping).            Remind the child to plan toilet times at specific times of the day (e.g., after meals, before going out, etc.).</p>
<p><b>Attention problems:</b>            Problems with registering the sensation of a full bladder or bowel.            Unable to sit for an adequate time on the toilet.</p>	<p>Increase fluid and fiber intake to increase bladder and bowel sensation            Sit on the toilet after accidents.            Accompany the child to the toilet, play favorite games, finger-play, tablet, music, and so forth.            Make the bathroom a welcoming and comfortable zone (warm, pictures, and toys).</p>
<p><b>Communication/speech impairments:</b>            Unable to communicate the urge or need to go to the toilet.            Unable to signal that he/she needs help.</p>	<p>Use signs, cards, signal words, or pictures as visual aids.            When children (mostly those with severe/profound ID) cannot report feelings of urge, body language should be observed. Some children show a specific behavior (e.g., holding maneuvers, etc.) before voiding/defecating.</p>
<p><b>Memory deficits:</b>            Problems with remembering to go to the toilet regularly, or in learning practical skills.</p>	<p>Charts, signals, timer watches can be helpful.            Many repetitions and a longer learning time are often necessary.            All caregivers in all situations should teach the child in the same way, and use the same routine to avoid confusing the child (e.g., mother and father at home, assistants in school, etc.).</p>
<p><b>Lack of motivation:</b>            Children may be more anxious and less motivated to learn new skills (e.g., switching from diaper to toilet).            Caregivers' and health professionals' expectations may be lower than what the child can actually learn.</p>	<p>Enhance learning processes or new behaviors by praising and rewarding, but not pressuring the child and offering alternatives.            Include intermediate steps (e.g., child defecates in the diaper but only in the bathroom, child can sit on the toilet with diapers on, etc.).            Motivate parents or caregivers to continue with training and give positive feedback for even small changes.</p>
<p><b>Motor impairments:</b> Coordination disorders, physical disabilities, or muscle hypo-/hypertonia can hinder children from going to or sitting on the toilet.</p>	<p>Carefully check what is possible and where the child will need help (e.g., with cleaning up).            Offer seat adjustments, armrests, foot-stools, and so forth, or advice from a physio/occupational therapist.</p>

Most children and adolescents with NDs have the same types of nonorganic incontinence as their typically developing peers. The basic principles of assessment and treatment, including standard and specific urotherapy, apply to children with NDs, in the same way as typically developing children.<sup>54</sup> Therefore, incontinence should be assessed and treated by experienced professionals in a

timely manner at the earliest age, avoiding diagnostic overshadowing.

However, NDs can pose an enormous challenge to incontinence treatment. Therefore, urotherapists and other professionals should be acquainted with basic aspects of NDs, as well as comorbid disorders. However, differences do exist between the different types of NDs.

### 3.11 | Treatment of incontinence in ADHD

As most children with ADHD do have an IQ in the normal range, the influence of ID affects only a minority of children. Hyperactivity, deficits in concentration, distractibility, and impulsivity can be difficult to handle in a nontreated child, while compliance will be much better under medication. If a child with typical signs of ADHD has not been assessed yet, referral for assessment is indicated. This can be performed by child psychiatrists, psychologists, behavioral–developmental as well as general pediatricians with skills in this field. Treatment of MPH or AMPH will increase compliance and motivation with better outcomes of incontinence therapy.<sup>4,20</sup> There is also evidence of an antienuretic effect of ADHD medication, especially atomoxetine and clonidine/guanfacine which could lead to synergic effects in the treatment of NE in children with ADHD.<sup>55–57</sup>

Special problems will be encountered in children with ADHD plus an ODD or a CD, as these children are prone to disruptive and rule-breaking behaviors. In addition to medication, CBT with simple token plans to reinforce compliance positively is indicated in most cases. In more problematic cases, withdrawal of positive reinforcers or even time-out procedures can be of help. Overall, a child with ADHD will be easier to treat individually than in a group setting. Parents should be involved to assure adherence to treatment in home settings.

Aspects of ADHD that may exacerbate incontinence and/or treatment of incontinence in children and adolescents, as well as possible interventions, are shown in Table 5.

### 3.12 | Treatment of incontinence in ASD

ASD is a much more severe disorder than ADHD, although both can co-occur. Many children with ASD also have ID. If ASD is suspected, a professional assessment in special centers is required. Depending on the manifestation of ASD symptoms, treatment of incontinence requires a lot of skill and patience from the urotherapist who will need an understanding of ASD cognition and behavior to be able to adapt and tailor-make urotherapy appropriately. More complex elements of CBT may be needed, such as prompting, fading, extinction, modeling, or other techniques derived from autism treatment programs. Special interests and specific sensory likes and dislikes can be incorporated into the treatment plan,

which should be based on behavioral analysis. Still, achieving continence will be of great relief for a child with ASD and parents alike.

Aspects of autism that may exacerbate incontinence and/or treatment of incontinence in children and adolescents with ASD, as well as useful interventions are outlined in Table 6.

### 3.13 | Treatment of incontinence in ID

The treatment of children with ID often needs to concentrate on basic aspects of urotherapy, such as timed voiding, sufficient oral fluids, toilet habits, and hygiene. Depending on the IQ level, direct reinforcements instead of delayed rewards through token systems are more effective. Complex CBT components may be needed such as prompting, fading and even aversive interventions (e.g., in case of self-harm or socially unacceptable fecal smearing). Often medication is more feasible than behavioral techniques (e.g., desmopressin instead of alarm treatment).<sup>3</sup> Parents, teachers, and caregivers need to be involved more intensely than in other NDs. Finally, in addition to IQ, the specific behavioral phenotype has to be considered in treatment planning.<sup>39</sup> Practical approaches to the treatment of incontinence in individuals with ID are shown in Table 7.

## 4 | CONCLUSIONS

NDs are commonly associated with incontinence in children and adolescents. The three most important NDs are ADHD, ASD, and ID. A specific diagnosis of the type of incontinence, the type of ND, and associated disorders is needed to initiate an effective treatment. Often, incontinence is neglected in the care of children with NDs. Most types of incontinence are nonorganic and continence can be achieved by the same approaches as in typically developing children, that is, standard and specific urotherapy and, if indicated, pharmacotherapy. Of the NDs, ASD and ID are more severe disorders than ADHD and can pose great challenges to professionals. Therefore, treatment of incontinence needs to be adapted and modified according to the special needs of this patient population. Professionals should have a basic knowledge of these disorders to deliver effective treatment. A multiprofessional approach is needed for optimal care.

### WEB RESOURCES

<https://www.bbuk.org.uk/wp-content/uploads/2018/05/Information-for-professionals-and-carers-re-toilet-training-with-autism-developmental-disabilities.pdf>

<https://www.bbuk.org.uk/wp-content/uploads/2018/03/Information-sheet-re-Toilet-training-children-with-additional-needs.pdf>

[https://do2learn.com/picturecards/printcards/selfhelp\\_toileting.htm](https://do2learn.com/picturecards/printcards/selfhelp_toileting.htm)

<https://continencevictoria.org.au/product/one-step-at-a-time-toilet-training-children-with-special-needs-pdf-download/>

## CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

## AUTHOR CONTRIBUTIONS

The paper was written by Alexander von Gontard, Justine Hussong, and Anne Wright; Janet Chase contributed actively towards aspects regarding urotherapy, adding many important practical points; Stephen S. Yang and Israel Franco contributed towards medical, neurobiological, and urological aspects ensuring that all standards were met; all authors read and contributed actively towards the revisions of the manuscript.

## DATA AVAILABILITY STATEMENT

Data available on request from the authors.

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