Neurodevelopmental disorders and incontinence in children and adolescents: Attention-deficit-/hyperactivity disorder (ADHD), Autism spectrum disorder (ASD) and Intellectual disability (ID) - a position document of the International Children's Continence Society (ICCS)

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Word count text: 4158

ABSTRACT

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 ICCS document is provide an overview of the three most important NDs, i.e. attention-deficit-/hyperactivity disorder, autism spectrum disorder and intellectual disability. Their relevance to professionals dealing with incontinence in children and adolescents will be outlined and practical information will be provided.

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

LIST OF 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
NDs	Neurodevelopmental disorders
NE	Nocturnal enuresis
ODD	Oppositional defiant disorder

INTRODUCTION

Neurodevelopmental disorders (NDs) are conditions, which begin early in life and are characterized by a wide variety of impairing developmental deficits (APA, 2013). The etiology of NDs encompasses mainly genetic and neurobiological factors and they show a tendency to persist, i.e. 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) (APA, 2013).

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 (Austin et al., 2016; von Gontard 2013; von Gontard and Equit 2015; Niemczyk et al. 2018). 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 (Crimmins et al. 2003).

So far, research has focused on the three major groups of NDs with especially high rates of NE, DUI and FI, i.e. ADHD, ASD and ID (von Gontard 2013; von Gontard and Equit 2015; Niemczyk et al. 2018). 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 in order 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.

METHODS

This position 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, non-systematic review with practical recommendations for the assessment and treatment of childhood incontinence in NDs.

RESULTS

Attention-deficit/hyperactivity disorder (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 e.g. 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 his or her turn e.g. while waiting in line'. Clinicians are referred to the DSM-5 for a full list of all items (APA, 2013).

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), predominately 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 (APA, 2013).

The worldwide prevalence of ADHD is 5% in children and 2.5% in adults. More boys than girls are affected (2-3:1) (Polanczyk et al., 2007). The heritability is high (0.7-0.8), i.e. 70-80% of the etiological variance can be explained by genetic factors (Faraone et al, 2005). ADHD is a polygenic disorder and several genes have been identified, including the dopamine-4 receptor, dopamine transporter and other genes (Gizer et al., 2009). ADHD can be diagnosed from the age of 3 years onwards (ZERO TO THREE, 2016)). 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 (ZERO TO THREE, 2016). ADHD is a chronic disorder: 2/3 of adolescents and 1/3 of adults with a childhood diagnosis are still affected (Biederman et al., 2000; Simon et al. 2009). ADHD carries long-term developmental risks for substance abuse and other disorders (Larson et al. 2011; Biederman et al. 1997; Barkley et al. 2004).

The rate of comorbid disorders in ADHD is high and two thirds of children are affected by at least one concomitant disorder (Larson et al. 2011). Typical disorders include oppositional defiant (ODD),

conduct (CD), depressive and anxiety disorders, specific developmental disorders like speech disorders, ASD and tic disorders (Wolraich et al. 2019; Larson et al. 2011).

Incontinence in ADHD

The rate of incontinence is increased in children with ADHD (von Gontard and Equit, 2015). Conversely, 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 (Joinson et al. 2006, 2006, 2007), as well as in other studies. Although 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 and epigenetic factors are discussed as common neurobiological factors (von Gontard and Equit 2015). Specific brain regions such as the anterior cingulate gyrus and the dorsal anterior midcingulate cortex are involved in both ADHD and incontinence (Franco, 2015).

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 (Crimmins et al. 2003; von Gontard & Equit, 2015). Therefore, the identification and treatment of ADHD is necessary in children with incontinence.

Assessment and treatment of ADHD

Several ADHD-guidelines have been issued in many countries, including the AAP (American Academy of Pediatrics) (Wolraich et al. 2019) for the USA, the NICE-guidelines for the UK (NICE 2018) and the AWMF-guidelines for Germany (Banaschewski et al. 2017).

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 (NICE 2018). ECG, EEG and laboratory tests are not mandatory, but can be indicated in certain cases (NICE 2018; Banaschewski 2017). For example, with preexisting cardiac disease in the child or family, ECG and further cardiology examinations may be indicated prior to initiating medication, particularly as there is potential for drug interaction, e.g. methylphenidate and imipramine. Imaging or genetic assessment is usually not indicated on a routine basis.

Counselling and provision of information for child, parents and, if indicated, teachers should be offered when a diagnosis of ADHD has been confirmed (NICE 2018). In mild cases and in preschool

children, psychosocial interventions (e.g. psychoeducation and parental training) should be conducted first and pharmacotherapy only if needed (Wolraich et al. 2019; Banaschewski et al. 2017). In moderate cases, psychosocial interventions can be combined with pharmacotherapy. In severe cases, an intensive psychosocial and pharmacotherapeutical approach is recommended (Banaschewski et al. 2017). Of all psychosocial interventions, cognitive behavioral therapy (CBT) is the most effective, which encompasses a wide range of different techniques (NICE, 2018). Of course, all comorbid disorders should be treated in addition to ADHD (Wolraich et al. 2019).

Neurofeedback, omega-3-fatty acids, diets, other forms of psychotherapy, occupational therapy are not, or only minimally, effective for core ADHD symptoms (Banaschewski et al., 2017; Wolraich et al. 2019). 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 methylphenidate (MPH), as a short- (3-4 hours) or, preferably, long-acting (6-10 hours) formulation. The main effect of MPH is to block presynaptic dopamine and noradrenalin re-uptake, thereby increasing dopamine and noradrenalin concentration in the synaptic cleft of the prefrontal cortex (Banaschewski et al. 2019; Volkow et al., 2002).

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 from 5mg-10mg/day in one dose in the morning (long-acting MPH) or two doses in the morning and at mid-day (short-acting MPH). The maximal dose is 0.8mg/kg body weight/day.

70% of children respond to MPH. Primary effects are a reduction of hyperactivity, an increased attention span and other cognitive effects such as an 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 (Banaschewski et al. 2017).

For those who do not respond or show marked side-effects to MPH, second-line medications are dexamphetamine or lys-dexamphetamine (NICE 2018). 90% of children respond to either MPH or amphetamines (AMPH). Amphetamines 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.

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 flexibly 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 with good effect sizes (NICE 2018). The main side-effects are gastrointestinal. Atomoxetine has to be taken every day, starting with 0.5mg/kg body weight/day, tapering up to 1.2mg/kg body weight/day in one dose in the morning with a 24-hour effect). The effects become apparent after 4-6 weeks.

Finally, forth-line medication is guanfacine, an alpha-adrenergic receptor-agonist (NICE 2018). The initial dose in 1mg/day in the morning, which can be increased in 1mg steps per week up to 4mg/day, again with a 24-hour 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). Other medication 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 autism spectrum disorder with disruptive symptoms) are present in the affected child. The basic principles of ADHD are summarized in table 1.

Autism spectrum disorder (ASD)

ASD is a severe ND with incapacitating symptoms in social interaction and communication or stereotyped-repetitive behaviors (APA, 2013). 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’. An 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 (APA, 2013).

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 (APA, 2013). The severity can vary from ‘requiring support’ to ‘requiring very substantial support’, i.e. in three major levels.

ASD can be recognized from the second year of life onwards. For young children, the diagnostic classification of mental health and developmental disorders of infancy and childhood (DC: 0-5) criteria are more sensitive (Zero to Three, 2016). The prevalence of ASD is approximately 1%. Five times more boys are affected than girls (Fuentes et al., 2014). The heritability for ASD lies between 64% and 91% (Tick et al., 2016) and environmental and epigenetic factors increase the risk of ASD (Fuentes 2014; APA, 2013). 15% of persons with ASD have a genetic syndrome (e.g. Fragile-X-syndrome, tuberous sclerosis). The remaining 85% of non-syndromic forms of ASD are oligo- or polygenic. 70% of children and adolescents have a comorbid psychiatric disorder (e.g. attention-deficit/hyperactivity disorder (ADHD), developmental disorders, anxiety, depression, sleep disorders) (Fuentes 2014; APA, 2013; NICE 2013). In addition, approximately half of children with ASD are affected by ID (Freitag and Vogeley; 2016).

Incontinence in ASD

The rates of NE are higher in ASD than in the normal population ranging from 2% up to 16-41% according to a systematic review (Niemczyk et al. 2017). DUI is also more prevalent in ASD than in typically developing persons, with rates of 4.3% to 55% in selected cohorts. NE and DUI can represent side-effects of medication such as risperidone or other antipsychotics. The range of FI varies from 2-12%. Children with ASD have a special risk for constipation and other functional gastro-intestinal disorders (McElhanon et al. 2014). Successful therapy outcome is lower than in the typically developing population (Gor et al., 2012). The treatment of incontinence in children with ASD is more time-consuming and needs a more structured and intensive behavioral approach (von Gontard, 2013; van Oorsouw, 2009; Hanney et al., 2013).

Assessment and treatment of ASD

The diagnosis of ASD requires a full mental health, as well as pediatric assessment (NICE 2011; Freitag and Vogeley 2016). The gold standard required for diagnosis includes the ADI-R parent interview, the ADOS observation scale, and an intelligence or developmental test (Freitag and Vogeley, 2016). Questionnaires and other specific instruments can be required. All comorbid disorders should be diagnosed (Freitag and Vogeley, 2016). Genetic assessment is recommended in every case. Imaging and further assessments (ENT, ophthalmology, neurology, etc.) are often required when specific symptoms are present.

The treatment of ASD includes parent training and counselling, as well as cognitive-behavioral therapy (NICE, 2013). All comorbid disorders should be addressed separately. If indicated, speech-, occupational- and physiotherapy can useful. Children and adolescents with ASD often require special education, assistance from social services and specific types of treatment developed for autism spectrum disorders, such as the TEACCH or ABA-programs and their variants. These should focus on increasing social skills and everyday competences, and fostering play and interactive strengths. Repetitive and stereotypic behavior should be restricted.

No specific medication is available for ASD (NICE 2013). 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 (NICE 2013).

ASD is usually a much more severe disorder than ADHD, which can impact on 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.

Intellectual disability

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, etc. Adaptive functioning refers to how well a person meets community standards in conceptual, social and practical domains (APA, 2013)

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 (< 1%) (REF).

The prevalence of ID is around 1-3.4% (Maulik et al., 2011). Males are overrepresented (1.5:1). ID is a heterogeneous conditions 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 (Lundvall et al., 2012; Strømme, 2000). 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. Idiopathic ID (no definite cause) is due to a polygenic-multifactorial transmission and mainly affects individuals with mild ID.

The identification of specific syndromes is not just important for genetic counselling, 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 (Flint and Yule, 1995REF?) Comorbid psychiatric disorders are common in individuals with ID, increasing from a rate of 33% in mild ID to 42% in severe ID (Stromme and Diseth, 2000).

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 (von Wendt et al., 1990). In addition, these rates remained high even at the age of 20 years. Most children and adolescents with ID have the same type of non-organic incontinence as typically developing individuals. Children with ID have more incomplete bladder emptying, interrupted uroflows and smaller bladder capacities than typically developing children (Yang et al., 2010).

In the meantime, studies on incontinence have been conducted in a wide spectrum of syndromes: For mild ID, on Down, Williams, Prader-Willi and Noonan syndromes and others; for moderate ID, Fragile-X and with severe or profound ID: Angelman, Mowat-Wilson, Phelan-McDermid and Rett syndromes (see table 3). 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 (Wagner et al., 2017; Giesbers et al., 2012). 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 (van Laecke et al., 2001). 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 (Downs syndrome) (von Gontard et al., 2016; Niemczyk et al., 2017).

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, Sparrow et al. 2016). 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 (Moeschler 2006).

ID cannot be cured. Persons with ID require special education and other social services. Speech-, occupational- and physiotherapy is 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.

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.

Most children and adolescents with NDs have the same types of non-organic 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 (Nieuwhof-Leppink et al. 2020). 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.

Treatment of incontinence in ADHD

Most children with ADHD have an IQ in the normal range. Hyperactivity, deficits in concentration, distractibility and impulsivity can be difficult to handle in a non-treated 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, psychologist, 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 (Crimmins et al., 2003; von Gontard and Equit, 20515). There is also evidence of an anti-enuretic effect of ADHD medication, especially atomoxetine (Sumner et al. 2006; Ohtomo, 2017) and clonidine/guanfacine (Ohtomo 2017) which could lead to synergic effects in the treatment of NE in children with ADHD.

Special problems will be encountered in children with ADHD plus an oppositional defiant disorder (ODD) or a conduct disorder (CD), as these children are prone to disruptive and rule-breaking behaviors. In addition to medication, cognitive-behavioral therapy (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.

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 in order to be able to adapt and tailor-make urotherapy appropriately. More complex elements of CBT may be needed, such as prompting, fading, extinction, modelling or other techniques derived from autism treatment programs. Special interests and specific sensory likes and dislikes can be incorporated in the treatment plan, which should be based on a 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.

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) (von Gontard, 2013). 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 (Flint and Yule, 1994). Practical approaches to the treatment of incontinence in individuals with ID are shown in table 7.

CONCLUSIONS

NDs are commonly associated with incontinence in children and adolescents. Often, incontinence is neglected in the care of children with NDs, although patients and parents can be highly incapacitated. Most types of incontinence are non-organic and continence can be achieved. A detailed assessment and specific treatment is possible and should be offered to all children with NDs. Therapy needs to be modified according to the special needs of this patient population. Professionals should have a basic knowledge of these disorders in order to deliver an effective treatment. A multiprofessional approach is optimal.

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Resources

https://www.bbuk.org.uk/wp-content/uploads/2018/05/Information-for-professionals-and-carers-re-toilet-training-with-autism-developmental-disabilties.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://continencevictoria.org.au/product/one-step-at-a-time-toilet-training-children-with-special-needs-pdf-download/

Table 1: ADHD – practical summary for clinicians in the incontinence field

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 DSM-5 criteria.
In young children, DC: 0-5 criteria are more specific.
Comorbid disorders of ADHD need to be diagnosed and assessed.
ADHD is a chronic disease with long-term developmental risks.
Counselling 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 psycho-social interventions; if not sufficient, medication.
In moderate cases: both psychosocial interventions and medication.
In severe cases: primarily medication, accompanied by psycho-social 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.

Table 2: ASD – practical summary for clinicians in the incontinence field

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 assessment 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.
Counselling 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.

Table 3: ID – practical summary for clinicians in the incontinence field

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.

Table 4: Selected syndromes of ID and associated incontinence prevalence

Syndromes	n	Ave age(range) years	ID-Level	NE %	DUI %	FI %	Publication
Noonan	29	15.2(5-48)	Mild	16.0	13.8	7.4	Niemczyk et al, 2015
Williams 7q11del	231	19.4(4.1-59.9)	Mild	17.8	5.9	7.6	von Gontard et al, 2016
Prader -Willi	118	20.5(5-45)	Mild	13.6	3.8	3.3	von Gontard et al, 2010; Equit et al, 2013
Trisomy 21/ Downs	317	19.2(4-51)	Moderate	17.2	15.9	14.2	Niemczyk et al, 2017
Fragile-X	22	11.1	Moderate-severe	45.5	36.4	31.8	Niemczyk et al, 2016; Equit et al, 2013
Angelman	153	15.1 (4-31)	Severe	81.0	61.4	53.9	Wagner et al, 2017
Mowat-Wilson	47	13.0(4-33)	Severe	97.7	76.2	81.4	Niemczyk et al, 2017
Rett	63	19.34(5-47)	Severe	98.4	96.8	57-72	Giesbers et al, 2012

Table 5: Specific ADHD problems regarding incontinence and helpful strategies

Problems in ADHD	**Helpful strategies**
Attention deficit (inability to concentrate or focus for a long period of time): Lower response to bladder sensation Distracted on the way to the bathroom Problems: Adhering to urotherapy Remembering drinking or toileting programs Remembering to void before sleep Remembering to take medication	Shorter training time (e.g. in urotherapy) Smaller units of information Smaller sequential steps of intervention (e.g. first implementation of regular fluid intake, then regular voiding, etc.) Use visual timetables and charts to create structure. Use timer watches (for voiding/drinking) Create predictability with a 'countdown warning' prior to changing activities. Increase parental support. Reward for cooperation (praise, tokens, rewards, other positive reinforcers etc.).
Hyperactivity (increased motor activity and difficulties with keeping still): Bowel toileting programs: child cannot sit still for longer periods of time on the toilet Urotherapy: Child cannot sit still in order to learn about bladder/bowel function	Include interactive games in educational setting Learning with the use of drawings and other hands-on materials. Provide positive feedback for all desired behaviors. Reward for sitting on the toilet for an adequate time. Increase the amount of time for sitting on the toilet (e.g. first week 5 min, second week 10 min). Use of a timer or other visual aids for timed toilet sitting. Include motivational input during sitting times (e.g. video games).
Impulsivity (inability to think before acting): Problems: Having a drink and forgetting to stick to fluid restriction rules when taking desmopressin	Introduce rules and reward adherence Increase parental or teacher surveillance/supervision (e.g. medication). Create a "stop signal" to remind the child to do something.

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	
Accompanying oppositional behaviors: Refusal to comply with urotherapy Refusal to listen to parents when sent to toilet Postponement of voiding (while playing, watching TV) Cheating (e. g. hiding soiled underwear) Aggressive behavior (shouting, kicking) when parents ask them to do something (go to toilet, drink, etc.)	Include smartphones, watches and other timers to remind the child to go to the toilet. Create comprehensible, measurable and objectifiable rules to avoid discussions Reward and praise the child when complying Selective ignoring of minor negative behavior (e.g. shouting) and reinforcement positive behavior. Avoid discussions, give constructive advice Give positive feedback, e.g. before going to bed ('What went well today?').

Table 6: Specific problems and helpful strategies regarding incontinence in ASD

Problems in ASD	**Helpful strategy:**
Deficits in social communication interaction: Child fails to communicate to a parent/caregiver of their need to void or defecate and thus does not receive support	Use structured visual timetables, incorporating toilet times. Hang chart in the toilet room with the steps of toileting in pictures and consistent use of a 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.
Deficits in social emotional reciprocity: 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, e.g., "I only wee if I feel the need".	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, etc. 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.
Restricted repetitive behaviors:	Careful history and observation distinguish between restricted and repetitive behaviors. Reinforce first void, not the following voids

Some children void repetitively as part of these restricted, repetitive behaviors and this may be mistaken for an overactive bladder.	Offer alternative games/activities that are interesting to avoid repetitions.
Restricted diet: Selective food intake and low fiber content may contribute to constipation. Administration of medication can be very difficult, e.g. Macrogol PEG3500 with electrolytes is often refused, even when added to fluids	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, 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.
Sensory issues: 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.	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, modelling clay, etc. 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.

Motor issues: 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.	Help with visual clues (pictures of all steps of a procedure). Use self-help clothing, seat adjustments, special seats, stools, armrests can be necessary. Backward Chaining; a technique whereby the child learns the last step in a series of tasks and progressively works backwards to give a sense of completion

Table 7: Typical problems and helpful strategies regarding incontinence in the individuals with ID

Problems in ID	**Helpful strategies**
Deficits in intellectual functioning: 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.	Teach child to sit on the toilet at times when voiding/defecating is probable (e.g. after mealtimes, every 1-2 hours 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, etc. 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, etc. (chaining, shaping). Remind the child to plan toilet times at specific times of the day (e.g. after meals, before going out, etc.).
Attention problems: Problems with registering the sensation of a full bladder or bowel. Unable to sit for an adequate time on the toilet.	Increase fluid and fiber intake to increase bladder and bowel sensation Sit on the toilet after accidents. Accompany child to the toilet, play favorite game, finger-play, tablet, music, etc. Make the bathroom a welcoming and comfortable zone (warm, pictures, toys).
Communication/speech impairments: Unable to communicate the urge or need to go to the toilet	Use signs, cards, signal words or pictures as visual aids.

Unable to signal that he/she needs help	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.) prior to voiding/defecating.
Memory deficits: Problems with remembering to go to the toilet regularly, or in learning practical skills	Charts, signals, timer watches can helpful. Many repetitions and a longer learning time is 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.).
Lack of motivation: 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.	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.
Motor impairments: - Coordination disorders, physical disabilities or muscle hypo-/hypertonia can hinder children from going to or sitting on the toilet.	Carefully check what is possible and where the child will need help (e.g. with cleaning up). Offer seat adjustments, armrests, foot-stools, etc. or advice from a physio/occupational therapist.