International Journal of Social and Humanities Sciences Research
JSHSR
Uluslararası Sosyal ve Beşeri Bilimler Araştırma Dergisi
Uluslararası Hakemli Dergi- International Refereed Journal
ISSN: 2459-1149

Received-Makale Geliş Tarihi 05.09.2026
Published-Yayınlanma Tarihi 31.10.2026
Volume-Cilt (Issue-Sayı), ss/pp 13 (136),1917-1924

Review Article / Derleme Makale
10.5281/zenodo.23837868

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ROR Id: https://ror.org/05rrfpt58

The Importance of Developmental Assessment in Pediatric Surgery: A Review of the Evidence on Hypospadias and Hirschsprung Disease

Çocuk Cerrahisinde Gelişimsel Değerlendirmenin Önemi: Hipospadias ve Hirschsprung Hastalığına İlişkin Kanıtların Derlemesi

ABSTRACT

Hypospadias and Hirschsprung disease are congenital conditions that require pediatric surgical and pediatric urological services to address anatomical and functional problems. However, long-term follow-up should also encompass children's developmental and psychosocial needs. This narrative review aims to summarize the basic characteristics and surgical treatment of these conditions, critically evaluate the evidence on developmental outcomes, and propose ways to integrate developmental screening and assessment into pediatric surgical services. The author's clinical experience in pediatric surgery motivated this review. Epidemiological studies, clinical guidelines, and publications examining neurodevelopmental, psychological, and educational outcomes were considered. Hypospadias has been associated with higher odds of certain neurodevelopmental diagnoses, whereas studies of psychological adjustment have reported variable findings. In Hirschsprung disease, some studies report favorable academic outcomes, while others indicate increased educational support needs. The available evidence is insufficient to establish a single generalizable estimate of the prevalence of developmental delay in either condition. Developmental screening results, neurodevelopmental diagnoses, psychological difficulties, and educational support needs should not be treated as interchangeable outcomes. Developmental follow-up is recommended as a complement to surgical and functional follow-up. To support this approach, the employment of child development specialists in pediatric surgery clinics in Türkiye is recommended, together with the inclusion of professionals with equivalent competencies in international practice. The feasibility of this service model and its effects on child outcomes should be evaluated in prospective research.
Keywords: Pediatric surgery, hypospadias, Hirschsprung disease, developmental assessment, child development specialist.

ÖZET

Hipospadias ve Hirschsprung hastalığı, anatomik ve işlevsel sorunların tedavisi için çocuk cerrahisi ve çocuk ürolojisi hizmetleri gerektiren doğumsal hastalıklardır. Bununla birlikte, çocukların uzun dönem izlemi gelişimsel ve psikososyal gereksinimleri de kapsamalıdır. Bu anlatısal derlemenin amacı, iki hastalığın temel özelliklerini ve cerrahi tedavilerini özetlemek, gelişimsel sonuçlara ilişkin kanıtları eleştirel olarak değerlendirmek ve gelişimsel tarama ile değerlendirmenin çocuk cerrahisi hizmetlerine bütünleştirilmesine yönelik öneriler sunmaktır. Yazar bu çalışmayı çocuk cerrahisi klinik deneyimlerinden hareketle yapmak istemiştir. Çalışma kapsamında; epidemiyolojik çalışmalar, klinik kılavuzlar ve nörogelişimsel, psikolojik ve eğitsel sonuçları inceleyen yayınlar değerlendirilmiştir. Hipospadias bazı nörogelişimsel tanıların artmış olasılığıyla ilişkilendirilirken, psikolojik uyuma ilişkin araştırmalarda değişken sonuçlar bildirilmiştir. Hirschsprung hastalığında bazı çalışmalar okul başarısına ilişkin olumlu sonuçlar, bazıları ise artmış eğitim desteği gereksinimi göstermektedir. Mevcut bulgular, her iki hastalık için genellenebilir tek bir gelişimsel gecikme yüzdesi vermeye yeterli değildir. Gelişimsel tarama sonuçları, nörogelişimsel tanılar, psikolojik güçlükler ve eğitim desteği gereksinimi birbirinin yerine kullanılmamalıdır. Çocukların gelişimsel izleminin cerrahi ve işlevsel izlemi tamamlaması önerilmektedir. Bu amaçla Türkiye'de çocuk cerrahisi kliniklerinde çocuk gelişimcilerinin istihdam edilmesi; uluslararası uygulamalarda ise eşdeğer yetkinliklere sahip meslek elemanlarının ekipte yer alması önerilmektedir. Bu hizmet modelinin uygulanabilirliği ve çocuk sonuçlarına etkisi ileriye dönük araştırmalarla değerlendirilmelidir.
Anahtar Kelimeler: Çocuk cerrahisi, hipospadias, Hirschsprung hastalığı, gelişimsel değerlendirme, çocuk gelişimci.

1. INTRODUCTION

Development in childhood encompasses the acquisition of cognitive, language and communication, gross and fine motor, social-emotional, and daily living skills, as well as changes in these skills over time. This concept extends beyond growth, which refers to increases in height and weight. Developmental assessment seeks to understand not only whether a child has a medical condition, but also what the child can do in relation to the child's age and living circumstances, which areas require support, and how these needs should be monitored. Developmental surveillance, standardized screening, and comprehensive assessment are related but distinct processes (Lipkin et al., 2020).

Hypospadias is a congenital anomaly characterized by a urethral opening located proximally on the ventral surface of the penis rather than at its usual position at the tip. European registry data indicate a prevalence of 18.61 cases per 10,000 total births; worldwide estimates vary considerably according to methodology and geographical region (Bergman et al., 2015; Springer et al., 2016). Hirschsprung disease is a congenital motility disorder caused by the absence of enteric ganglion cells in the distal bowel and occurs in approximately 1 in 5,000 births (Kyrklund et al., 2020). Although surgery is important in both conditions, children's developmental and psychosocial needs also require assessment.

Developmental assessment and screening services are provided in hospital child development units in Türkiye. The responsibilities of child development specialists include assessing developmental domains, preparing developmental support programs tailored to each child's needs, contributing to the follow-up of children at risk under the supervision of the relevant specialist, and providing family counseling and education (Akkaş & Tozduman Yaralı, 2022; Sağlık Bakanlığı, 2014). These services are part of interdisciplinary care; developmental assessment and medical diagnosis of neurodevelopmental conditions are distinct processes. Nevertheless, these processes can complement one another within transdisciplinary teamwork that addresses the needs of the child and family holistically (Tercan & Yıldız Bıçakçı, 2016).

This review aims to provide basic information on the definition, frequency, and surgical treatment of hypospadias and Hirschsprung disease; examine the evidence on developmental, psychosocial, and educational outcomes in these conditions; raise awareness of these aspects of care; and discuss the role of developmental screening and assessment in pediatric surgery clinics. It also presents a service development proposal for the employment of child development specialists within clinical teams.

2. METHODS

This study is a focused narrative review. Selected epidemiological studies, clinical guidelines, and developmental outcome studies were examined using PubMed records, accessible journal articles, institutional publication records, and relevant official sources. Searches were conducted in English and Turkish on hypospadias, Hirschsprung disease, developmental delay, neurodevelopment, psychosocial adjustment, and educational outcomes. Sources were selected on the basis of disease specificity, study design, and relevance to the review questions. The included publications with identifiable publication dates spanned 2001–2026. The literature search was completed on August 2, 2026. Bibliographic verification and further consultation of the selected sources continued after this date.

This study is neither a systematic review nor a meta-analysis.Disease-specific studies were considered separately from findings derived from broader groups of gastrointestinal anomalies. Percentages and effect estimates were interpreted in relation to each study's sample and measured outcome; no new rates were derived from incomplete information.

3. BASIC CHARACTERISTICS OF HYPOSPADIAS

3.1. Definition and Clinical Features

In hypospadias, the urethral opening may be located anywhere from the glanular or subcoronal region to the penile, penoscrotal, or perineal region. Ventral penile curvature and abnormalities of preputial development may also be present. Assessment considers not only the location of the opening but also curvature, the urethral plate, and surrounding tissues. Decisions about the need for surgery and the choice of operative technique are individualized according to anatomical characteristics and functional problems (European Association of Urology [EAU], n.d.).

3.2. Global and Turkish Data

In their review of publications covering approximately 90 million births, Springer et al. (2016) showed that the frequency of hypospadias varies substantially across regions and studies. A single estimate should therefore not be assumed to represent the entire world. In a study using 23 EUROCAT registries, Bergman et al. (2015) identified 10,929 cases among 5,871,855 births between 2001 and 2010, yielding a prevalence of 18.61 per 10,000 total births. The denominator included both female and male births, rather than male births alone.

In a prospective study conducted at a single teaching hospital in Istanbul, Türkiye, Akın et al. (2011) identified hypospadias in 34 of 1,750 male infants born between September 2007 and December 2008. The authors reported rates of 19.4 per 1,000 live male births and 93.7 per 10,000 total live births. This was a single-center study, not a national prevalence estimate. This high local estimate should not be compared directly with rates from other countries without considering differences in diagnosis and recording practices. A current nationally representative estimate for Türkiye could not be verified in this review.

3.3. Surgical Treatment and Follow-Up

Hypospadias repair is reconstructive surgery that includes correction of curvature when needed, construction of a urethra of adequate caliber, and relocation of the opening to the glans. Tubularized incised plate urethroplasty is commonly used for distal and mid-penile cases. More severe proximal cases may require flaps or grafts and staged repairs. Primary repair is usually performed between 6 and 18 months of age. Fistula, stenosis, wound or glans dehiscence, and recurrent curvature may require additional procedures (EAU, n.d.). Hypospadias is therefore not a uniform surgical condition associated with the same treatment burden in every child.

4. BASIC CHARACTERISTICS OF HIRSCHSPRUNG DISEASE

4.1. Definition and Frequency

In Hirschsprung disease, the absence of ganglion cells in the distal bowel causes functional obstruction. The condition can affect varying lengths of bowel; approximately 80–85% of cases are limited to the rectosigmoid region. The overall frequency is approximately 1 in 5,000 births, with a male-to-female ratio of approximately 4:1 (Kyrklund et al., 2020). These are international reference estimates and should not be presented as population-based rates specific to Türkiye.

Hospital-based studies of congenital anomalies have been conducted in Türkiye. For example, Türkbay et al. (2020) examined selected anomalies among 102,379 live births and highlighted data limitations in determining the country's true burden of congenital anomalies. However, hospital-based data alone are insufficient to estimate national prevalence. As this review could not identify a verified national estimate of the birth prevalence of Hirschsprung disease in Türkiye, no country-specific numerical estimate is provided.

4.2. Diagnosis and Surgical Treatment

Diagnosis is based on histopathological examination of an adequate rectal biopsy. Definitive treatment involves removing the aganglionic segment and bringing ganglionated bowel down to the anal region. Pull-through operations include endorectal, Swenson-type, and Duhamel approaches and may be performed using transanal, laparoscopic-assisted, or open techniques. Depending on the clinical situation, a preliminary stoma may be required. Bowel dysfunction and enterocolitis may occur after surgery. Follow-up should encompass multidisciplinary care and transition to adult services (Kyrklund et al., 2020).

5. DEVELOPMENTAL SCREENING, ASSESSMENT, AND SURVEILLANCE

5.1. Conceptual Distinctions

Developmental screening uses standardized tools to identify children who may require further assessment. Developmental assessment examines strengths and difficulties across developmental domains more comprehensively and in greater detail. Developmental surveillance is a longitudinal process that brings together information on family concerns, developmental history, observation of the child, and environmental circumstances over time in a holistic manner. The American Academy of Pediatrics recommends developmental surveillance at every well-child visit and standardized general developmental screening at 9, 18, and 30 months. Additional screening or direct referral should follow when concerns

arise. These are general child health recommendations, rather than a screening schedule specifically validated for hypospadias or Hirschsprung disease (Lipkin et al., 2020).

Developmental delay refers to the acquisition of developmental skills later than expected. In contrast, intellectual disability, autism spectrum disorder, and attention-deficit/hyperactivity disorder (ADHD) are neurodevelopmental conditions with distinct diagnostic criteria. Educational support needs and low quality of life are likewise not synonymous with developmental delay. Reporting one of these outcomes in a study does not indicate that the others occur at the same frequency.

5.2. The Role of Child Development Specialists in Hospitals

The Ministry of Health's job description specifies that child development specialists are responsible for assessment and needs-based developmental support in cognitive, language, motor, self-care, social, and emotional domains (Sağlık Bakanlığı, 2014). Reports of hospital practice also describe developmental screening and assessment services (Akkaş & Tozduman Yaralı, 2022). In addition to outpatient clinics, child development specialists conduct developmental screening and assessment in pediatric inpatient wards, provide developmental and psychosocial support to children, and offer counseling to families. These responsibilities focus on the child's developmental profile and on supporting the family. The selection of tools, methods, and techniques for developmental screening, assessment, and follow-up should take into account professional training, practitioner competence, and the intended purposes and conditions of use. Collaboration with the relevant units should be established for medical diagnosis or assessments requiring other specialist expertise. Ideally, such collaboration should follow a pathway progressing from a multidisciplinary approach toward a transdisciplinary approach.

6. DEVELOPMENTAL AND PSYCHOSOCIAL EVIDENCE IN HYPOSPADIAS

6.1. Reported Frequency of Developmental Difficulties

Wu et al. (2002) reviewed the records of 356 patients who underwent surgery and reported disorders related to physical and mental development in 21 patients (5.9%). This category combined diverse conditions, including growth retardation, cerebral palsy, and psychological disorders affecting functioning. Posterior hypospadias accounted for 65.7% of the sample. The 5.9% figure therefore cannot be used as the prevalence of developmental delay measured with a standardized instrument in all children with hypospadias. It should be interpreted as a finding from a historical surgical series with a high proportion of severe cases. Cakmak et al. (2022) assessed 78 boys with hypospadias and 59 boys presenting for circumcision using parent-completed ASQ and ASQ-SE screening instruments. Boys with hypospadias showed significantly greater difficulties in communication, gross motor, and personal-social domains. In multivariate logistic regression, hypospadias independently predicted difficulties in communication and personal-social skills. These screening findings support attention to developmental needs but should not be interpreted as confirmed neurodevelopmental diagnoses.

6.2. Neurodevelopmental Diagnoses

The Swedish national registry study by Butwicka et al. (2015) included 9,262 males with hypospadias and 4,936 unaffected brothers. Compared with controls, the hypospadias group had an odds ratio (OR) of 3.2 for intellectual disability (95% confidence interval [CI]: 2.8–3.8), 1.4 for autism spectrum disorder (1.2–1.7), and 1.5 for ADHD (1.3–1.9). The higher frequency of autism diagnoses among unaffected brothers suggests a possible contribution of shared familial factors.

These estimates are not absolute frequencies. For example, an OR of 3.2 does not mean that 32% of children have intellectual disability. The study demonstrates associations with recorded diagnoses; it does not establish that hypospadias, surgery, or anesthesia causes these diagnoses. Moreover, the findings do not establish separate prevalence estimates for language and motor delays (Butwicka et al., 2015).

6.3. Psychological Adjustment and Quality of Life

Sandberg et al. (2001) compared 175 children aged 6–10 years with a history of surgery with 333 community controls and found few significant differences between the groups. School performance was not lower, while greater surgical and hospital exposure was associated with internalizing problems. This observational association does not establish that these experiences directly caused the difficulties.

Schönbucher et al. (2008) compared 77 children with hypospadias aged 7–17 years with 77 children who had undergone hernia repair. Although child-reported quality of life was lower in most domains, no group differences were found in mother-reported quality of life or psychological adjustment. Perceptions of

penile appearance and experiences of teasing were associated with outcomes. These findings support listening to children's own experiences in a developmentally appropriate way alongside obtaining parents' views.

7. DEVELOPMENTAL AND EDUCATIONAL EVIDENCE IN HIRSCHSPRUNG DISEASE

7.1. School Readiness and Academic Outcomes

Cowap et al. (2022) examined educational outcomes in 75 children with isolated Hirschsprung disease. Failure to meet expectations on the Early Development Instrument was reported more frequently in the preschool period, but no increased risk of failing standardized tests or not completing high school was identified after school entry. These findings are encouraging; however, the small sample, restriction to isolated disease, and the use of educational outcomes as indirect indicators of development should be considered. Later achievement does not mean that children never required support at earlier stages.

7.2. Attention-Deficit/Hyperactivity Disorder

In a Swedish study, Löf Granström et al. (2019) compared 739 individuals with Hirschsprung disease with 7,390 controls. ADHD was diagnosed in 26 and 202 individuals, respectively, corresponding to approximately 3.5% and 2.7%. The OR was 1.30 (95% CI: 0.84–1.93), indicating no statistically significant increase. This finding neither establishes that all developmental domains are unaffected nor supports the claim that ADHD is necessarily more frequent in this condition.

7.3. Educational Support Needs

In a study linking health and education records in England, Harron et al. (2026) reported that special educational needs were recorded for 44.0% of children with Hirschsprung disease who were linked to school records at approximately six years of age, compared with 17.9% of children in the comparison group. The incidence rate ratio reported in the adjusted analysis was 1.34 (95% CI: 1.24–1.45). This outcome also includes support provided for physical needs, and the 44.0% figure should not be presented as the prevalence of developmental delay. Receiving educational support and achieving appropriate academic outcomes can coexist; the findings therefore do not necessarily conflict with those of Cowap et al. (2022).

7.4. Cognitive, Motor, and Language Development

In their meta-analysis of 47 studies involving 2,312 patients, Roorda et al. (2021) found that children with congenital gastrointestinal anomalies had lower cognitive, motor, and language scores relative to the comparison data. The standardized mean differences were −0.435, −0.610, and −0.670, respectively. These values are not percentages of children with developmental delay. Because the colorectal subgroup included both Hirschsprung disease and anorectal malformations, the results cannot be regarded as specific to Hirschsprung disease. Although associations with length of hospital stay and number of operations were reported, causal effects of surgery cannot be inferred because of disease severity and other confounders. Between-study heterogeneity and possible publication bias further limit interpretation.

8. DISCUSSION

The central finding of this review is that developmental needs warrant attention in both conditions, but the available findings cannot be summarized as a single rate of developmental delay. Table 1 brings together selected numerical findings and the limits of their interpretation. Recorded neurodevelopmental diagnoses, developmental screening performance, and school support needs are distinct outcomes. Combining them under a single heading may create a misleading perception of risk for children and families.

Table 1. Development-Related Outcomes in Selected Studies

Study / Group	Outcome Measured	Main Finding	Limit of Interpretation
Wu et al. (2002) / Hypospadias	Diverse disorders related to physical and mental development	21/356 (5.9%)	Not a standardized estimate of developmental delay prevalence.
Cakmak et al. (2022) / Hypospadias	ASQ and ASQ-SE developmental screening	78 cases and 59 controls; greater difficulties in communication, gross motor, and personal-social domains	Screening findings do not establish clinical diagnoses or causality.
Butwicka et al. (2015) / Hypospadias	Recorded neurodevelopmental diagnoses	Intellectual disability OR 3.2; autism OR 1.4; ADHD OR 1.5	ORs are not absolute percentages and do not establish causality.
Cowap et al. (2022) / Isolated Hirschsprung disease	Preschool assessment and subsequent educational achievement	75 cases; preschool difficulties, with no increased risk of subsequent academic failure	Educational outcomes are not direct clinical diagnoses.
Löf Granström et al. (2019) / Hirschsprung disease	ADHD diagnosis	26/739 and 202/7,390; OR 1.30 (95% CI: 0.84–1.93)	No statistically significant increase was demonstrated.
Harron et al. (2026) / Hirschsprung disease	Special educational needs and support requirements recorded at school	44.0% versus 17.9%; adjusted ratio 1.34	Includes physical needs; not a percentage of developmental delay.
Roorda et al. (2021) / Various gastrointestinal anomalies	Cognitive, motor, and language scores	47 studies; 2,312 patients; lower scores	Neither a Hirschsprung-specific finding nor a percentage of developmental delay.

Source: Prepared from the studies listed in the table. OR: odds ratio; CI: confidence interval; ADHD: attention-deficit/hyperactivity disorder. Percentages and effect estimates concern different outcomes and should not be pooled.

In hypospadias, national registry data demonstrate associations with specific neurodevelopmental diagnoses, whereas studies examining children's overall behavioral adjustment may yield more favorable findings (Butwicka et al., 2015; Sandberg et al., 2001). This illustrates how different measures address different questions. Rather than characterizing all children as a group expected to experience developmental delay, assessment should focus on individual developmental profiles and expressed needs.

In Hirschsprung disease, greater use of educational support does not necessarily indicate lower intellectual ability. Physical care needs, learning difficulties, and school accommodations may be reflected in the same support record (Harron et al., 2026). Clinical assessment should distinguish bowel-related difficulties from developmental level while considering their combined effects on daily life. Educational achievement and support needs are not mutually exclusive.

The rationale proposed for incorporating developmental screening into surgical follow-up is to facilitate the identification of children who need support and their access to appropriate services, rather than to presume a disorder in every child. Nevertheless, the evidence base of this review does not include an intervention study directly demonstrating that employing child development specialists improves outcomes in hypospadias or Hirschsprung disease. This may reflect the limited recognition of child development specialists in clinical practice owing to their restricted employment in the health sector, despite their status as university-trained health professionals. The employment recommendation is therefore a service development proposal based on existing developmental findings and professional responsibilities; the effects of this proposal require further investigation.

8.1. Limitations and Research Needs

Narrative source selection, reliance on accessible publications, and the absence of a formal quality assessment are limitations of this review. Studies differ in age, disease severity, associated conditions, assessment instruments, and follow-up duration. Some reflect historical surgical practices. Further population-based prevalence data for Türkiye and disease-specific developmental research are needed. Future studies should examine cognitive, language, motor, social-emotional, and adaptive domains through repeated assessments, distinguish isolated from syndromic cases, and document access to interventions.

9. CONCLUSIONS AND RECOMMENDATIONS

Follow-up of hypospadias and Hirschsprung disease should encompass the child's developmental status alongside anatomical and functional outcomes. Existing studies report findings that warrant attention regarding selected neurodevelopmental diagnoses, psychosocial experiences, and developmental and educational support needs. However, neither a single estimate of the prevalence of developmental delay applicable to all patients nor a causal effect of surgery has been established.

9.1. Incorporating Developmental Screening and Assessment into Follow-Up

At surgical follow-up visits, clinicians should document family concerns and the child's developmental history, check whether routine child health assessments and developmental screening have been completed, and arrange referral for standardized screening or comprehensive assessment when needed. Instruments should be appropriate for the child's age, language, and culture, and practitioner competence should be ensured. Screening results alone should not be presented as a medical diagnosis, and access to services following referral should be monitored.

9.2. Employment Of Child Development Specialists in Pediatric Surgery Clinics

The employment of child development specialists in pediatric surgery clinics in Türkiye is recommended to provide developmental screening and assessment and to monitor children for developmental delay in children with hypospadias and Hirschsprung disease. Their inclusion in surgical teams should be planned to support developmental history-taking, screening, assessment, and follow-up; provide families with guidance to support development; offer bedside developmental and psychosocial support to children admitted to surgical wards; and coordinate referral to relevant units when necessary.

Internationally, the employment of professionals capable of performing these functions within pediatric surgical services is also recommended, in accordance with each country's professional training and scope-of-practice regulations. The same professional title and scope of responsibilities should not be assumed to exist across countries. This recommendation does not represent an existing international requirement; it proposes an approach to care that supports multidisciplinary collaboration and, under appropriate conditions, transdisciplinary teamwork. The role of the child development specialist within a transdisciplinary team has also been discussed in the health sciences literature (Tercan & Yıldız Bıçakçı, 2016).

9.3. Evaluating the Service Model

In centers where child development specialists can be employed, responsibilities and referral pathways should be defined in writing. Institutions with limited resources may establish regular consultation and shared follow-up arrangements with a child development unit. Implementation should be evaluated through screening coverage, time to assessment, referral completion rates, family experience, and children's developmental outcomes. This would allow the benefits, feasibility, and resource requirements of the proposed service model to be measured.

AI Disclosure: During the preparation of this manuscript, the author utilized an artificial intelligence tool for English language editing, grammar correction, and improving stylistic clarity.

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