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The Challenges of Child and Adolescent Psychiatrists in the Process of the Disability Report Evaluation

Heyet Raporu Değerlendirme Sürecinde Çocuk ve Ergen Psikiyatristlerin Yaşadıkları Zorluklar

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ABSTRACT

This study aimed to identify the challenges faced by child and adolescent psychiatrists on reporting Intellectual & Developmental Disability during the disability evaluation process in Turkey, One hundred five child and adolescent psychiatrists agreed to participate in the study. We asked them to complete an online questionnaire that was prepared for this study. The major challenge of the process was determining whether the disability is severe or not. On the other hand, the age range that the participants had the most difficulty in the process was preschool. As a result, child and adolescent psychiatrist had essential difficulties while evaluating children with Intellectual & Developmental Disabilities. As a solution, medical diagnosis and functionality should be evaluated together in order to determine the disability level and whether disability is severe or not.

Keywords: Benefits, Child and Adolescent Psychiatrist, Developmental Disability, Intellectual Disability, Reporting**.**

ÖZ

Bu çalışma, çocuk ve ergen psikiyatrlarının Türkiye'de özel gereksinimi değerlendirme sürecinde Entellektüel Yeti Yitimi ve Bilişsel Gelişim Geriliği'ni raporlamada karşılaştıkları zorlukları tespit etmeyi amaçlamıştır. Yüz beş çocuk ve ergen psikiyatrist çalışmaya katılmayı kabul etti. Katılımcılardan, bu çalışma için hazırlanan çevrimiçi bir anketi doldurmaları istendi. Katılımcılar, sürecin kendileri için en büyük zorluğunun gereksinimin ciddi olup olmadığının belirlenmesi olduğunu belirttiler. Öte yandan, katılımcıların bu süreçte en fazla zorluk yaşadığı yaş aralığı okulöncesi idi. Sonuç olarak, çocuk ve ergen psikiyatristleri Entellektüel Yeti Yitimi ve Bilişsel Gelişim Geriliği tanılı çocukları değerlendirirken önemli zorluklarla karşılaşmıştır. Çözüm olarak, gereksinim düzeyini ve gereksinimin şiddetli olup olmadığını belirlemek için tıbbi tanı ve işlevsellik birlikte değerlendirilmesi gereklidir.

Anahtar Kelimeler: Bilişsel Gelişim Geriliği Çocuk ve Ergen Psikiyatrisi, Entellektüel Yeti Yitimi, İmkanlar, Raporlama.

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INTRODUCTION

The World Health Organisation (WHO) defines disability as an umbrella term, which covers impairments, activity limitations, and participation restrictions due to health conditions.[1] Nevertheless, in Turkey, as in many countries, the definition and evaluation of disability vary according to the intended use, such as use for legal issues or benefit from social rights. For instance, the United States Social Security Administration widely defines childhood disability as a medically identifiable physical or mental problem that throws out at least 12 months and causes severe and significant functional limitations and is expected to result in death.[2,3] Accordingly, it is critical to acknowledge that there is no globally accepted description of childhood disability.[3-6]

Children with special health care needs (CSHCN) are described as children with disability, who face challenges owing to chronic physical, developmental, behavioural, or emotional conditions, in terms of their individual traits and educational competencies. CSHCN require health, special education and related services of a type or amount beyond that required by children generally.[3,7-9] The requirements of CSHCN vary from the severity and level of the disability; and also the presence of additional disabilities are among the critical determinant.[10,11]

Within the scope of the disability evaluation process in Turkey, the level of the CSHCNs' disability, and whether the CSHCNs' disability severe or not are determined, and this process is finalized in a decision report, which is called a disability report. The disability report prepared by the health board is required for CSHN and their parents to apply for Social Security Disability Benefits. Benefits provided vary from country to country; special education and financial contribution are among the most common opportunities provided by many countries.[3-5,12,13] The level of disability is determined according to legislation, based on the medical diagnosis based on international disease classification (ICD-10). For instance, according to legislations, the level of disability determined for the diagnosis of mild intellectual disability is 50% for moderate intellectual disability 70% and 90% for profound intellectual disability. According to the legislation, severe disability defines those whose disability level is evaluated as 50% or more and cannot meet individual daily requirements without any help. Accordingly, there are two boxes to put a checkmark on the disability report, whether the current disability is severe; yes, and no.[5,14]

In United States, special education and related services are presented by The Individuals with Disabilities Education Act. In Turkey, the name of the institution that provides special education is General Directorate of Special Education and Guidance Services. In Turkey, like many other countries, after taking a disability report, General Directorate of Special Education and Guidance Services perform assessments to identify the additional educational needs of the CSHCN.[12,15] In United States, almost six million CSHCN receive special education services related to their disability.[16] Furthermore, another essential benefit provided by the government is financial support to parents of CSHCN. The amount of financial benefits varied according to both level of disability and whether the disability is severe or not.[17]

The exact number of CSHCN is challenging to mention because of the inconsistent descriptions of what constitutes a disability used by various nationwide data collection sources. In a sample study published by the State Institute of Statistics of Turkey in 2004, the percentage of CSHCN in children and adolescent age groups was 8.78%.[18,] The WHO reported that as much as 20% of children and adolescents have a disabling mental disorder worldwide and Intellectual disability is the most common mental disorder evaluated within the scope of disability.[3,19-21]

Intellectual Disability begins in childhood and is characterized by impairments in both intelligence and adaptive functioning, with varying severity. Developmental disability is used to describe intellectual and adaptive impairment in infants and preschool children.[22,23] In Turkey, Child and adolescent psychiatry is the medical branch that is legally responsible for evaluating Intellectual & Developmental Disabilities in the disability evaluation process and psychologists and child development experts take part in assessments by performing developmental screening tests or psychometric measurements.

In Turkey, Child and adolescent psychiatry was instituted as a separate specialty since 1989.[24] Turkey is one of the most youthful nations of Europe. A third of the population being under the age of 18. World Health Organization's (WHO) state that the neuropsychiatric conditions in children and adolescents will cause a disproportionately large burden of disease. However, in Turkey, like other countries, the number of child and adolescent psychiatrists is quite insufficient. The ratio of child and adolescent psychiatrists remains at around 1 per 44,715 children and adolescents. Thirty-two percent of the total number of Child and adolescent psychiatrists work in university settings as academics. Fifty-eight per cent of them work in state hospitals as specialists/specialist clinicians.[25-26]

Until now, many studies have been conducted on the prevalence and sociodemographic characteristics of CSHCN.[27,28] However, as far as we know, there is no research on challenges faced by child and adolescent psychiatrists in the disability evaluation process. This study aimed to identify;

- The challenges faced by child and adolescent psychiatrists in the disability evaluation process for children with intellectual and developmental disability in Turkey.

MATERIALS AND METHODS

We sent an email to members of The National Child and Adolescent Psychiatry and Mental Health Association of Turkey and gave detailed information about the scope of the study. One hundred five child and adolescent psychiatrists agreed to participate in the study. We asked them to complete an online questionnaire that was prepared for this study. This research was carried out between 2018-2019. The questionnaire was prepared after a thorough review of the literature on the disability evaluation process toward CSHCN by authors of current research. The questionnaire includes; sociodemographic characteristics of the participants, years of occupational experience, occupational position (academician or specialist), work intensity (taking into account the number of examined patients per week), quantity and quality of assistant personnel (i.e. psychologists, child development specialists), in which age group did they have more difficulties in the evaluation process?, name of diagnostic tools and intelligence/development tests, which tests they used during the evaluation process and challenges during the evaluation process etc. This questionnaire was first piloted by twenty children and adolescent psychiatrists in order to check the clarity of the questions and choices. The questionnaire was also designed to include both closed and open-ended questions. The open-ended questions provided the opportunity for individuals to explain and elaborate on their views. We classified similar answers to the same group.

Ethical Aspect of Research

We received the necessary permission from the Ethical Committee of the Ataturk University Medical Faculty (29 March 2018, 118).

Data Analysis

Statistical analyses were performed using the Statistical Package for Social Sciences Statistics (SPSS) 20.0 program. Numerical variables were presented as mean and standard deviation (S.D.). Categorical data are given as numbers and percentages. Mann-Whitney U test or Student t-test was used among the groups depending on whether the variables show normal distribution or not. Pearson's chi-square and Fisher's exact tests were used to assessing the distribution of categorical variables. The statistical significance level was accepted as p <0.05.

Limitation of Research

This study used a questionnaire-based survey methodology, so this study is expected to have the limitations expected from all survey-based studies. Furthermore, since this study did not include all the child and adolescent psychiatrists, who were working in Turkey, the results of the study cannot be generalized to the whole country. Moreover, since only a few studies were done on this subject, it was not possible to discuss the results of our study globally.

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RESULTS AND DISCUSSION

The data on the amount of occupational experience and work intensity of all participants are presented in Table 1.

Table 1. The Data Collected From The Child And Adolescent Psychiatrists

		Child and Adolescent Psychiatrists (n=105)
Experience in Years	Mean ± SD	3.7±3.8
Number of Outpatient Patients	Mean ± SD (per week)	116.3±62.7
Number of CSHCN Applications	Mean ± SD (per week)	34.8±35.3
How many minutes does the evaluation process take?	Mean ± SD	14.9±9.3

SD: *Standard Deviation*

In preschool children in the disability evaluation process, 53.3% (n=56) of participants used the Denver II Developmental Screening Test, 39% (n=41) of participants used the Ankara Developmental Screening Inventory and 7.7% (n=9) of participants used other development tests. There was no significant difference between the specialists and academicians on the developmental tests used in the evaluation process (p>0.05). Eighty (76.2%) participants indicated that developmental tests did not provide an adequate contribution to the final decision on the disability evaluation process, and due to this reason, they should be updated. Seventy-three (69.5%) participants stated that the number of assistant personnel was not sufficient in their clinic. Eighty-one (77.1%) participants reported that Intelligence Quotient (I.Q.)/developmental tests, which were performed by the assistant personnel, did not contribute to the final decision on disability evaluation process at the desired level for various reasons, such as inadequate experience on carrying out I.Q./developmental tests. There were no significant differences among the specialists and academicians on whether having a sufficient number of assistant personnel and also having assistant personnel with adequate experience (p>0.05).

In the disability evaluation process, eighty (76.9%) participants used their clinical experience, while twenty-four (23.1%) participants used the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria and I.Q./ Developmental test scores. There was no significant difference between the specialists and academicians in terms of the diagnostic tools used in the evaluation process (p>0.05). Participants, who use clinical experience, made more disability evaluation per week (p = 0.014, z = - 2.450). Furthermore, even not statistically significant, they also had both an insufficient number of assistant personnel and more assistant personnel with inadequate experience, and they also further stated that development tests should be updated.

The challenging issues, which faced by participants in the disability evaluation process, were the determination of the severity of the disability 57.8% (n=59) and the level of the disability 42.2% (n=43). During the disability evaluation process, while seventy-three (70.2%) participants stated that they had the most difficulties in preschool children, thirty-one (29.8%) participants had the most difficulties in school-age children and adolescents. There were no significant differences between the specialists and academicians on challenging issues and age range with difficulty during the disability evaluation process (p>0.05). Even not statistically significant, participants, who use clinical experience, stated that they had less difficulty in determination of the whether disability severe or not. Moreover, even not statistically significant, participants, who stated that they had difficulty whether the disability is severe or not, allocated a shorter time to the disability assessment process. Similarly, even not statistically significant, participants, who stated that they had difficulty whether the disability is severe or not, had not got a sufficient number of assistant personnel and their assistant personnel had also inadequate experience.

Eighty-three (79%) participants stated that genetic diagnosis and forty-seven (44.8%) participants stated that chronic physical diseases (deafness, blind etc.) were not a component of the disability evaluation process on intellectual and developmental disabilities. Moreover, Thirty-two (30.5%) of participants claimed that the final decision of the disability evaluation process showed inconsistency among the child and adolescent psychiatrists. Participants re-evaluated an average of two CSHCN per week who objected to the disability report, and the most common reasons for objections to disability reports were the severity of the disability 69.7% (n=69) and the level of the disability 30.3% (n=30). Participants, who had not got a sufficient number of assistant personnel, were less likely to direct to specific education for children diagnosed with the stimulus-poor environment (p=0.013). The significant differences between specialists and academics are shown in Tables 2.

Table 2. Comparison of Specialists and Academics

	Specialists (n=73)	***Academics (n=32)***	***p value***
Experience in Years	3.1±3.6	5.5±3.8	**<0.001* (z=-3,868)**
Number of Outpatient Patients (per week)	129.5±49.2	86.3±79.1	**<0.001* (z=-4,440)**
Number of Disability Report Applications (per week)	37.8±34.9	27.9±35.8	**0.021* (z=-2,305)**
How many minutes does the evaluation process take?	12.4±7.1	20.6±11.3	**<0.001** (t=-3,818)**
The Tendency to Refer a CSHCN for Special Education n (%)			
Child with Borderline Mental Capacity	7 (9.7%)	14 (43.8%)	**<0.001*** (X^2=15.91)**
Child with Partial Developmental Delay	3 (4.2%)	6 (18.8%)	**0.023*** (X^2=5.96)**
Child with Developmental Disability (under the age of one)	15 (20.8%)	20 (62.5%)	**<0.001*** (X^2=17.22)**
Follow the CSHCN Regularly (Yes) n (%)	50 (68.5%)	28 (87.5%)	**0.040*** (X^2=4.2)**

Mann-Whitney U test, **Student t test, ***Chi-squared test,* ***SD:* *Standart Deviation*

Intellectual & Developmental Disabilities are an essential public health problem due to its prevalence and the requirement for relevant services, such as educational, financial. Therefore, it is necessary to provide easy access to health services and appropriate supports within the scope of Intellectual Disability management. The quality of life for CSHCN and the quality of the service provided to them are considered one of the most important indicators of the level of development of a society in terms of health, education, and the economy.[13,23,29] In this context, this study set out to identify the challenges faced by the child and adolescent psychiatrists in the disability report evaluation process on children with Intellectual & Developmental Disabilities.

Intellectual & Developmental Disabilities diagnosis, which have two critical conditions, such as I.Q., Developmental screening tests, and difficulties in adaptive functioning, are highly heterogeneous and comprise a diverse spectrum of functioning and impairments and needs.[23,29] Because of highly heterogeneous, the evaluation process is complicated and quite tricky consisting of many steps. Nevertheless, it may be affected by many parameters, such as the experience of the psychiatrist and also assistant personnel, the time duration of the evaluation process, and diagnostic instruments used.

In the current study, participants stated that they had some difficulties while evaluating children with Intellectual & Developmental Disabilities. The main challenges in the disability evaluation process can be divided into two areas. The most difficult one among them was determining whether the disability is severe or not. Another one was the determination of the level of the disability. Similarly, reasons for the objection to disability report were the severity of the disability and the level of the disability, respectively. It was quite noteworthy that there were similarities between the reasons for objection by parents and the main challenges faced by the child and adolescent psychiatrists. In a study by Keten et al. (2012), the reasons for objections to disability reports in adults were examined, and reasons were the level of the disability, the severity of the disability, and both the level and the severity of the disability, respectively.[30] Although the results of this study were similar to the current study results, it was thought that the difference might be due to the age range of the participants in the studies.

Nevertheless, the I.Q. score is no longer the main feature used to classify the Intellectual Disability severity, even though the International Classification of Diseases, the 10th revision (ICD-10) codes continue to use the I.Q. scores. In Turkey, the disability report legislation is prepared with ICD-10 guiding. In this case, I.Q. scores, in the evaluation process, might have caused too much consideration by participants.[5] I.Q. score only facilitates the classification of Intellectual Disability. However, if the assessment of adaptive skills is not complete, the medical diagnosis may be incorrect, and at the same time, severe disability assessment cannot be performed. Because the absence of significant adaptive impairment (even though the I.Q. score is <70) restrains a diagnosis of Intellectual Disability and also the severity of the disability is determined by taking into account the degree of impairment in adaptive function and the level of support required.[23,29,31] Participants, who stated that they had difficulty whether the disability is severe or not, allocated a shorter time to the disability assessment process; due to this reason, another possible cause for this challenge may be that the duration of the disability evaluation process is quite short. Adaptive functions may not have been adequately evaluated due to limited evaluation time.

In the disability evaluation process, while 76.9% of the child and adolescent psychiatrists used their clinical experience, 23.1% of the child and adolescent psychiatrists used DSM-5 and/or intelligence/development test scores. Furthermore, the child and adolescent psychiatrists, who preferred using clinical experience, evaluated a significantly higher number of CSHCN and re-evaluated more reports due to objection, per week. And also, they had more qualitative and quantitative deficiencies of assistant personnel. The qualitative and quantitative deficiencies of psychologists and time constraints due to intensive numbers of CSHCN evaluations per week were considered to be the reasons for preferring evaluations based on clinical experience. The clinical experience-based assessments is a DSM-based evaluation type, although, it is completed in a much shorter time than DSM-5-based evaluations because it is completely unstructured.[32] Evaluations based on clinical experience allow the child and adolescent psychiatrists to get decisions in a short time without any help from the psychologists in the disability evaluation process. Moreover, clinical experience usually tends to over ascertain compared to strict criteria, as DSM-5. This situation may have been the other reason for the reliance on clinical experience. Nevertheless, clinical factors inform instrument selection, administration, and interpretation; due to this reason, clinical assessment is an important complement to standardized testing. Correspondingly, participants, who used their clinical experience instead of the I.Q. score, stated that they had less difficulty in assessing severe disability. Clinical evaluation plays an essential role in determining the strengths, needs and limitations of CSHCN, because it is expected that clinical assessment provides more opportunity to evaluate adaptive functions of CSHCN than DSM-5 and I.Q..[33]

Within the scope of current study, the age range, which was found the most difficult in the evaluation process by participants, was investigated. Participants had more difficulty with preschool-age children. The I.Q. test provides an appropriate classification since the disability reports format is prepared under the guidance of ICD 10.[34] Nevertheless, unlike I.Q. tests, developmental screening tests address four domains of child development: personal-social skills, fine motor and adaptive skills, gross motor skills and language skills, and so, developmental screening tests do not show concordance with the disability reports format[35]. As a consequence, in the evaluation process of preschool children, due to using developmental screening tests, is relatively more difficult than evaluation of school-age children. In addition to this, "Severely Disabled" defines an individual who cannot fulfill their daily activities without the help of others.[5] Even preschool children with typical development are dependent on their parents, so it is quite challenging to assess whether they are severely disabled. As a result, considering all these situations, it is easy to understand why children and adolescent psychiatrists experience more difficulties in the evaluation process for preschool-age children.

An important reason for objections to reports is contradictions between evaluators.[32] Similar to in the literature, an important percentage of the child and adolescent psychiatrists stated that the reporting of disability evaluation process did not show consistency between evaluators. It was determined that most of the child and adolescent psychiatrists, who claimed a discrepancy, preferred using their clinical experience in the process. A problem frequently encountered in studies in which unstructured clinical interviews are preferred is the contradictions among the evaluators.[34] As a consequence, evaluations based on clinical experience may have contributed to discrepancies in the final decision of disability report. In addition to this, developmental screening tests are used in preschool age, and they do not show concordance with the disability report format, leaving the interpretation of the data obtained entirely to the children and adolescent psychiatrists. After all, it is sure to see discrepancies between the evaluators, since a standard assessment cannot be made. In the reporting of disability evaluating process, more than half of the child and adolescent psychiatrists did not accept that the genetic diagnosis was a component of the evaluation process and approximately half of the child and adolescent psychiatrists did not also accept that physical problem (deafness, blind etc.) was a component of the evaluation process. These different approaches may also additional contributions to the contradictions between the evaluators. As a natural consequence of these issues, it may lead to an increased objection to disability reports.

Children diagnosed with borderline intellectual functioning and children with partial developmental delays, who did not fulfill any diagnostic criteria, as well as children diagnosed with global developmental delay before the age of one were referred to special education by academics more than specialists. It may be related to the higher tendency of academicians to direct children to special education, to have more experience and to allocate more to the disability report evaluation process in parallel with low working intensity.

CONCLUSION AND RECOMMENDATIONS

This study is the first study on the challenges faced by the child and adolescent psychiatrists who play a primary role in the disability evaluation process for CSHCN. Thus, data obtained from our research are expected to form the basis for future studies on reporting the disability evaluation process. The results show that the main challenge faced by child and adolescent psychiatrists in the process of disability report evaluation is related to the method used in the evaluation process of the disabled child. The level of disability, in Turkey, is determined by considering only the medical diagnosis in mental disorder practice. This may lead to loss of financial benefits for an individual with greater loss of functionality among individuals with the same medical diagnosis. "Severely Disabled" is mostly defined for adult age group. According to this definition, it is not clear which CSHCN, particularly before the age of six, will be admitted with "Severely Disabled". Moreover, the absence of a globally accepted definition of childhood disability makes it even more difficult to draw borders in the concept of "Severely Disabled". In order to solve this problem, a new definition for "Severely Disabled" is required for the childhood age group.

In conclusion, the approach in which functionality and medical diagnosis are evaluated together may solve many problems by facilitating the reporting process and reducing objections. Thus, internal consistency between doctors can be achieved, objections also can be reduced, CSHCN' supporting by social benefits immediately (especially special education) and benefits can be distributed fairly. Furthermore, increasing the number and experience of assistant personnel and the most important one increasing the number of child and adolescent psychiatrists. By this means, it will have expected that it may provide sufficient time for the evaluation process, contribute to their regular monitoring of CSHCN in the outpatient clinic and reduce the workload of doctors.

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