

Is It Really Accessible? A Qualitative Study About School Accessibility

Gerçekten Erişilebilir Mi? Okul Erişilebilirliği Hakkında Nitel Bir Çalışma

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ABSTRACT

Purpose: Cerebral palsy (CP) refers to a group of disorders; occurring as a result of a non-progressive impairment of the developing central nervous system. Participation of individuals with CP could be influenced by environmental factors. Therefore, the aim of our study is to identify how universally designed school environment effects the participation level of the individuals with CP. **Material and Methods:** The study was done in a state school where individuals with CP are educated. Semi-structured interviews with the student and the family were done to identify the barriers for school participation. Gross motor skills of individuals with CP were evaluated by The Gross Motor Function Classification System (GMFCS), hand functions were evaluated by Manual Ability Classification System (MACS) and communication skills were evaluated by Communication Function Classification System (CFCS). Data were analyzed by SPSS 21 and semi-structured interviews were analyzed with MAXQDA. **Results:** 28 individuals with CP (m:16, f:12) between 15-20 years (mean 16.9 ± 1.3 years) were included in the study. Participation problems during elevator and toilet use and architectural layout of recreational areas were indicated as causes of participation problems (p<0.05). **Discussion:** In addition to designing the environment in accordance with the principles of universal design, development of an interdisciplinary teamwork in which occupational therapists and architects will collaborate is important to ensure the full participation of individuals with disabilities in schools.

Keywords: Cerebral palsy; Environment design; Social participation; Qualitative research; Architectural accessibility

ÖZ

Amaç: Serebral palsi (SP), merkezi sinir sisteminin ilerleyici olmayan bozulmasının sonucu olarak ortaya çıkan bir grup bozukluğu ifade eder. SP'li bireylerin katılımları çevresel faktörlerden etkilenebilmektedir. Bu nedenle, çalışmamızın amacı, SP'li bireyler için özel olarak evrensel tasarım kurallarına uygun olarak dizayn edilmiş okul ortamının SP'li bireylerin katılım düzeyini nasıl etkilediğini araştırmaktır. **Gereç ve Yöntem:** Çalışma, SP'li bireylerin öğrenim gördüğü bir Anadolu Lisesi'nde yapıldı. Okula katılımın analizini yapmak için öğrenci ve aile ile yarı yapılandırılmış görüşmeler yapıldı. Bireylerin kaba motor becerileri Kaba Fonksiyon Sınıflandırma Sistemi (GMFCS) ile; el becerileri El Becerileri Sınıflandırma Sistemi (MACS) ile; iletişim becerileri ise İletişim Becerileri Sınıflandırma Sistemi (CFCS) ile değerlendirildi. Nicel veriler SPSS 21 ile değerlendirilirken; nitel veriler MAXQDA ile analiz edildi. **Sonuçlar:** Çalışmaya 15-20 yaş arası (ortalama 16.9 ± 1.3 yaş) 28 SP'li birey (e: 16, k: 12) dahil edildi. Asansör ve tuvalet kullanımı sırasındaki katılım sorunları ve rekreasyon alanlarının mimari yerleşimi okul katılımını olumsuz etkileyen sorunlar olarak tespit edildi (p<0.05). **Tartışma:** Evrensel tasarım prensiplerine uygun dizaynlar yapılmasının yanında ergoterapist ve mimarların ortak çalışma alanlarının geliştirilmesi engelli bireylerin okullarda tam katılımlarının sağlamak için önemlidir.

Anahtar kelimeler: Serebral palsi; Çevre tasarımı; Sosyal katılım; Nitel araştırma; Mimari erişilebilirlik

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Received (Geliş Tarihi): 15.01.2019; Accepted (Kabul Tarihi): 28.08.2019

This study has been carried out within the scope of "2017-1-TR01-KA203-046577 PUDCAD-Practicing Universal Design Principles in Design-a-CAD-Based Game" Project. It was presented as an oral presentation at 11 th Perception Lab Symposium and Man, Space and Inclusion.

Participation is a complex concept that is influenced by personal factors related to the child, family as well as by environmental factors (King, Lawm, King et al, 2003). Participation in home, school, and community activities has a positive impact on individuals' health, development, and wellbeing (Larson, 2000; Larson and Verma, 1999). Ecological-based models of childhood development, the biopsychosocial-based International Classification of Functioning, Disability and Health Framework for Child and Youth (ICF-CY) describe the characteristics of childhood functions; guide the selection of measurement tools; determine meaningful outcomes; and identify the environment as a key factor influencing participation (Anaby, Hand, Bradley et al, 2013).

Individuals with disabilities highlights the physical, social, attitudinal and institutional environments as key factors contributing to individuals' participation aligned with the ICF-CY (Anaby, Law, Coster et al, 2014). In many situations, particularly for those having persistent chronic conditions, changing child's environment is more feasible than changing child's abilities/skills, body structure and functions. The environment mediates the relationship between the complexity of a child's condition (disability, health condition, functional issues) and participation (ie, frequency and involvement) (Di Marino, Tremblay, Khetani et al, 2018).

The Universal Declaration of Human Rights which defines the rights of persons with disabilities with expression of "Recognizing that promoting the full participation and participation of people with disabilities in the welfare and diversity of the community and the positive contributions and obstacles they may make to human rights and fundamental freedoms contribute to their social belonging, their human, social and economic development and the reduction of poverty" and many different provisions, and emphasizes universally designed products and services to meet the specific needs of the disabled (Lauterpacht, 1948). In addition, the development of the minimum standards and guidelines for access to facilities and services that are open to the public or to public service has been materialized within the scope of accessibility. The availability of disabled people in society, the equal use of all areas should be achieved with easy access, secure, healthy, comfortable public spaces (Özhancı, Akıbaşında and Tırnakçı, 2018). World Disability Report (2011) listed the obstacles that should be handled under the six titles that one of them is overcoming obstacles in education (WHO,

2011).

Participation in school is conceived as an essential condition for constructing knowledge of the world, learning and development (Thomas, Warner, and Foster, 2000; Wadsworth, 1996; Sigel, & Cocking, 1977). Coster (1998) defines participation at school as the extent to which a child is able to orchestrate engagement in occupations in the school context that meets individual needs and goals as well as societal expectations. Moreover, the school years are a key developmental period when children and young people with disabilities learn both academic skills and life skills (Coster, 1998). Achieving social and economic participation on par with other members of the community is only possible for individuals with disabilities if they can commence life with appropriate educational opportunities (Rutkowski and Riehle, 2009; Bines and Lei, 2011). Research indicates that schooling can be fraught for individuals with disabilities due to physical barriers (Colver, Dickinson, Parkinson, et al, 2011).

Individuals with CP can be accompanied by disturbances of sensation, cognition, communication, perception, and/or seizure disorder which cause participation problems (Larson, 2000; Larson & Verma, 1999). Research into the equitable access to education for students with CP within school environment has rarely been studied (Bourke-Taylor, Cotter, Lator, et al, 2018). Moreover, Schenker, Coster and Parush (2005) recommend the revealing the environmental factors that enable and restrict full participation of individuals with CP in school environments. Therefore, the purpose of this study is to analyze the environmental context of a special school for individuals with CP and identify/discuss how school environment effects the participation level of the individuals with CP.

MATERIAL AND METHODS

The study was done in a special high school built according to universal design principles which are equitable use, flexibility in use, simple and intuitive use, perceptible information, tolerance for error, low physical effort and size and space for approach and use for adolescents with CP (Gülbahar, 2017). All the assessments was done by an occupational therapist. The school environment which consist of 16 classrooms, 16 workshops, 5 laboratories, 1 library, 2 guard waiting rooms, 1 gymnasium, 1 conference hall and 1 dining hall were evaluated for accessibility by the occupational therapist.

To analyze the school participation level of the students semi-structured interviews with the student

and the family were done additionally individuals' capability assessments. To assess individuals' capability The Gross Motor Function Classification System, Manual Ability Classification System and Communication Function Classification System were used.

Gross Motor Function Classification System (GMFCS) for CP is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. It is a 5 level clinical classification system that describes the gross motor function of people with CP (Rosenbaum, Palisano, Walter et al, 1997). The five levels of GMFCS is given in Table I (Hidecker, Ho, Dodge et al, 2012).

Manual Ability Classification System (MACS) describes how individuals with CP use their hands to handle objects in Daily activities. MACS describes

bilateral manuel activities with five levels based on the individuals' self-initiated ability to handle objects and their need for assistance or adaptation to perform bilateral activities in everday life (Eliasson, Krumlind-Sundholm, Rösblad et al., 2006). The five levels of MACS is given in Table I (Hidecker, et al, 2012).

Communication Function Classification System (CFCS) is a tool used to classify the everyday communication of an individual with CP into one of five levels according to effectiveness of communication. It consists of five levels which describe everyday communication ability. A person classified at Level I is a more able communicator than a person classified at Level V (Hidecker, Paneth, Rosenbaum et al, 2011). The five levels of MACS is given in Table 1 (Hidecker, et al, 2012).

Table 1. The five levels of GMFCS, MACS, and CFCS.

Classification systems			
Level	GMFCS	MACS	CFCS
I	Walks without limitations	Handles objects easily and successfully	Sends and receives information with familiar and unfamiliar partners effectively and efficiently
II	Walks with limitations	Handles most objects but with somewhat reduced quality and/or speed of achievement	Sends and receives information with familiar and unfamiliar partners but may need extra time
III	Walks using a hand-held mobility device	Handles objects with difficulty; needs help to prepare and/or modify activities	Sends and receives information with familiar partners effectively, but not with unfamiliar partners
IV	Self-mobility with limitations; may use powered mobility	Handles a limited selection of easily managed objects in adapted situations	Inconsistently sends and/or receives information even with familiar partners
V	Transported in a manual wheelchair	Does not handle objects and has severely limited ability to perform even simple actions	Seldom effectively sends and receives information even with familiar partners

GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System; CFCS, Communication Function Classification System.

The study was done according to Helsinki Declaration and all individuals with CP and their parents were informed about the study and their consent was obtained. Data was analyzed by SPSS 21 and semi-structured interviews were analyzed with MAXQDA. The process of qualitative content analysis often begins during the early stages of data

collection, and includes open coding, creation of categories and abstraction. Open coding means that notes and headings are written in the text while reading it. After open coding, the lists of categories are reduced and grouped under higher-order headings. When formulating categories by inductive content analysis, the researcher comes to a decision,

through interpretation, as to which items to place within the same category. Abstraction means formulating a general description of the research topic through generation of categories, each category being named using content-characteristic words. Sub-categories with similar events and incidents are grouped together as categories, and categories are grouped as main categories (Elo and Kyngäs, 2008).

RESULTS

A total of 28 individuals with CP (m:16, f:12) with an age range of 15 to 20 years (mean 16.9 ± 1.3 years) were included. Descriptive information from students, including GMFCS, MACS, and CFCS levels, is presented for 28 students with CP in Table 2.

Table 2. Characteristics of the students with cerebral palsy.

Characteristics	All n=28 (100%)
Sex	
Female	12 (43)
Male	16 (57)
Age, y (mean +SD)	
	16.9±1.3
Used assistive devices	
Wheelchairs (manual or powered)	15 (54)
Walkers	3 (11)
Ankle foot orthoses (AFO)/splints	10 (36)
Others (standing table, hearing aid)	3 (8)
GMFCS level	
I	7 (25)
II-III	9 (32)
IV-V	12 (43)
MACS level	
I-II	16 (57)
III-IV	11 (39)
V	1 (4)
CMFCS level	
I	7 (25)
II	18 (64)
III	1 (4)
IV	2 (7)
V	-

Seven (25%) of individuals with CP were classed at Gross Motor Function Classification System (GMFCS) level I; nine of individuals with CP (32%) at GMFCS level II/III; and twelve of individuals with CP (43%) at GMFCS level IV/V. Sixteen of individuals with CP (57%) were classed at MACS level I/II; eleven of individuals with CP (39%) at MACS level III/IV; one of individuals with CP (4%) at MACS level V. According to CFCS seven of individuals with CP (25%) classed at Level I, eighteen of individuals with CP (64%) were classed at Level II, one of individuals with CP (4%) were classed at Level III and two of individuals with CP (7%) was classed at Level IV. The individuals with CP used various assistive

devices (Table 2). According to the results of semi-structured interviews with the students and the families seven of adolescents with CP pointed out that elevator button was high and small to press. Furthermore, they emphasized that the elevator doesn't have a floor location indicator, not user-friendly because of chip and not large enough. Fifteen of them remarked that clothes tree at classes were too high and useless. Twelve of them signified problem about toilet accessibility and using. These problems were door weight; sink height; faucet, soap dispensers and hand dryers using. The students also pointed out that gymnasium, conference hall and dining hall were too far from main building.

DISCUSSION

The present study aimed to analyze the environmental context of a special school for individuals with CP and identify/discuss how school environment effects the participation level of the individuals with CP. It was seen that although the school is a special designed school which met the universal design criteria; the students with CP even had problems about elevators and toilet using in addition to reaching problems to recreational or activity areas.

Our results compatible with the literature demonstrate that differences between gross motor capability can affect the level of school participation of students with CP (Anaby, et al, 2013). Results also indicate that individuals with CP who has similar GMFCS scores could have different participation levels. As participation occurs in different contexts such as home, school, and outdoors or community and the participation level can be affected by environmental factors (Law, Finkelman, Hurley et al, 2004; Tieman, Palisano, Gracely et al, 2004).

The variation in skills of the child with CP may affect the participation level so it seems participation is dependent to the environmental context (Law, Haight, Milroy et al, 1999). During analyzing the level of participation environmental features must be analyzed which can facilitate or hinder participation. By comparing a child's capability and participation; universal design environments are seen very vital for the individuals with CP (Lenker and Perez, 2014). Even students with CP have problems with using the elevators, toilets and access to recreational and sports areas in school; accessible designed schools enhance activity participation of students with disability (Žgur, 2012). The environment is served as a mediator between CP factors and participation has clinical implications. Similar to the literature in the present study the environment is more amenable to change compared with the adolescent's health conditions and their functioning abilities (Bourke-Taylor, et al, 2018). Therefore, our results suggest occupational therapists should examine performance in the settings that are important to the child's daily life and work with architects.

The participation level varied across the home, school, and community settings (Lawlor, Mihaylov, Welsh et al, 2006). Therefore, special designed contexts such as school may improve the activity participation of the individuals with CP. Understanding the environmental factors (physical, social, and attitudinal) and personal factors contributing to the performance of participation may

enable occupational therapists to improve the participation level of individuals with CP in schools. Further interdisciplinary research including occupational therapists and architects is necessary to understand the contextual features that affect occupational participation in schools for disabled individuals.

Limited number of individuals, lacking of control group and analyzing just one school which is designed for individuals with CP may limit to globalize the results of our study but this is the first study done in a special designed school for individuals with CP.

References

- Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & et al. (2013). The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disabil Rehabil*, 35(19), 1589-1598.
- Anaby, D., Law, M., Coster, W., Bedell, G., Khetani, M., Avery, L., & et al. (2014). The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school, and community. *Arch Phys Med Rehabil*, 95(5), 908-917.
- Bines, H., & Lei, P. (2011). Disability and education: The longest road to inclusion. *Int J Educ Dev*, 31(5), 419-424.
- Bourke-Taylor, H. M., Cotter, C., Lalor, A., & Johnson, L. (2018). School success and participation for students with cerebral palsy: A qualitative study exploring multiple perspectives. *Disabil Rehabil*, 40(18), 2163-2171.
- Colver, A. F., Dickinson, H. O., Parkinson, K., Arnaud, C., Beckung, E., Fauconnier, J., & et al. (2011). Access of children with cerebral palsy to the physical, social and attitudinal environment they need: a cross-sectional European study. *Disabil Rehabil*, 33(1), 28-35.
- Coster, W. (1998). Occupation-centred assessment of children. *Am J Occup Ther*, 52(5), 337- 344. <https://doi.org/10.5014/ajot.52.5.337>
- Di Marino, E., Tremblay, S., Khetani, M., & Anaby, D. (2018). The effect of child, family and environmental factors on the participation of young children with disabilities. *Disabil Health J*, 11(1), 36-42.
- Eliasson, A. C., Krumlinde-Sundholm, L., Rösblad, B., Beckung, E., Arner, M., Öhrvall, A. M., & et al. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. *Dev Med Child Neurol*, 48(7), 549-554.
- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *J Adv Nurs*, 62(1), 107-115.
- Gülbahar, S. (2017). *An Investigation On Life Center Unit's Design Criteria In Inclusive Education Environments: A Case Study On Serçevesi Accessible Vocational High School* (Doctoral Dissertation). Institute of Social Sciences, Istanbul Technical University, Istanbul.
- Hidecker, M. J. C., Ho, N. T., Dodge, N., Hurvitz, E. A., Slaughter, J., Workinger, M. S., & et al. (2012). Inter-relationships of functional status in cerebral palsy:

- analyzing gross motor function, manual ability, and communication function classification systems in children. *Dev Med Child Neurol*, 54(8), 737-742.
- Hidecker, M. J. C., Paneth, N., Rosenbaum, P. L., Kent, R. D., Lillie, J., Eulenberg, J. B., & et al. (2011). Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Dev Med Child Neurol*, 53(8), 704-710.
- King, G., Lawm, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. L. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Phys Occup Ther Pediatr*, 23(1), 63-90.
- Larson, R. W. (2000). Toward a psychology of positive youth development. *Am Psychol*, 55(1), 170.
- Larson, R. W., & Verma, S. (1999). How children and adolescents spend time across the world: work, play, and developmental opportunities. *Psychol Bull*, 125(6), 701.
- Lauterpacht, H. (1948). The Universal Declaration of Human Rights. *Brit. YB Int'l L.*, 25, 354.
- Law, M., Finkelman, S., Hurley, P., Rosenbaum, P., King, S., King, G., & et al. (2004). Participation of children with physical disabilities: relationships with diagnosis, physical function, and demographic variables. *Scand J Occup Ther*, 11(4), 156-162.
- Law, M., Haight, M., Milroy, B., Willms, D., Stewart, D., & Rosenbaum, P. (1999). Environmental factors affecting the occupations of children with physical disabilities. *J Occup Sci*, 6(3), 102-110.
- Lawlor, K., Mihaylov, S., Welsh, B., Jarvis, S., & Colver, A. (2006). A qualitative study of the physical, social and attitudinal environments influencing the participation of children with cerebral palsy in northeast England. *Pediatr Rehabil*, 9(3), 219-228.
- Lenker, J., & Perez, B. (2014). The role of occupational therapists in universal design research. *Occupational Therapy Now*, 16(5), 13.
- Özhancı, E., Aklıbaşında, M., & Tırnakçı, A. (2018). The disability standards and unimpeded design at Nevşehir Hacı Bektas Veli University Campus. *Akademik Ziraat Dergisi*, 7(1), 83-92.
- Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Dev Med Child Neurol*, 39(4), 214-223.
- Rutkowski, S., & Riehle, E. (2009). Access to employment and economic independence in cerebral palsy. *Physical Medicine and Rehabilitation Clinics*, 20(3), 535-547.
- Schenker, R., Coster, W., & Parush, S. (2005). Participation and activity performance of students with cerebral palsy within the school environment. *Disabil Rehabil*, 27(10), 539-552.
- Sigel, I. E., & Cocking, R. R. (1977). *Cognitive development from childhood to adolescence: A constructivist perspective*. New York, USA: Holt, Rinehart and Winston.
- Thomas, R. M., Warner, N., & Foster, J. (2000). *Comparing theories of child development*. California, USA: Wadsworth.
- Tieman, B. L., Palisano, R. J., Gracely, E. J., & Rosenbaum, P. L. (2004). Gross motor capability and performance of mobility in children with cerebral palsy: a comparison across home, school, and outdoors/community settings. *Physical Therapy*, 84(5), 419-429.
- Wadsworth, B. J. (1996). *Piaget's theory of cognitive and affective development: Foundations of constructivism*. New York, USA: Longman Publishing.
- World Health Organization. (2011). *World report on disability*: World Health Organization.
- Žgur, E. (2012). School process role for children with cerebral palsy. *East J Med*, 17(4), 213-216.