

**VISOKA ZDRAVSTVENA ŠOLA V CELJU**

**DIPLOMSKO DELO**

**VLOGA DRUŽINE PRI RAZVOJU OTROKA Z DOWNOVIM  
SINDROMOM**

**THE ROLE OF THE FAMILY IN THE TREATMENT OF A CHILD WITH  
DOWN SYNDROME**

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## POVZETEK

**Uvod:** Downov sindrom, poimenovan po dr. Langdonu Downu, ki je njegove značilnosti prepoznal že leta 1866, je motnja v genskem zapisu, natančneje na 21. kromosomu, zato se imenuje tudi Trisomija 21. Ljudje s to motnjo imajo v vsaki celici 47 kromosomov, namesto običajnih 46. Imajo značilne telesne znake in so pogosto tudi duševno zaostali. Vse osebe nimajo enakih značilnosti in enake stopnje le-te. Med njimi obstajajo velike razlike kot med drugimi ljudmi. Danes jih v vseh pogledih vključujemo v družbo in jim zagotavljamo pravice, zapisane v ustavi. Naš namen je bil raziskati, kakšna je vloga družine pri razvoju otroka z Downovim sindromom.

**Metoda:** Raziskava je temeljila na kvalitativni metodi raziskovanja. S staršema otroka z Downovim sindromom smo izvedli polstrukturiran intervju, iz katerega smo, glede na postavljena raziskovalna vprašanja, določili kode in jih združili v kategorije, nato pa jih primerjali s strokovno literaturo.

**Rezultati:** Trinajstletnica s tipičnimi telesnimi znaki, značilnimi za ljudi z Downovim sindromom, je danes vključena v poseben prilagojen program znotraj šole s prilagojenim programom, saj njihovega učnega programa ni zmogla, kar kaže na težjo motnjo kognitivnega področju. Zelo spretna, v primerjavi s sebi enakimi, je na motoričnem področju, katerega tudi starši najbolj spodbujajo. Z zdravjem ni imela posebnih težav. Družina je pozitivno naravnana do situacije, sprejela jo je takšno, kot je in ji ves čas nudi popolno podporo v smeri čim bolj samostojnega življenja.

**Razprava in sklep:** Ugotavljamo, da je družina ključna pri razvoju otroka z Downovim sindromom. Poleg skrbi zanj in nenehnega ukvarjanja z njim je njena naloga tudi, da ga redno vključuje v aktivnosti, potrebne za otrokov uspešen razvoj, sodeluje s strokovnjaki različnih strok in tudi doma deluje po njihovih priporočilih. Poleg omenjenega mora skrbeti, da so člani med seboj tesno povezani ter pozitivno naravnani, saj je družinska klima ključna pri razvoju otroka s posebnimi potrebami.

**Ključne besede:** Downov sindromom, obravnava otroka z Downovim sindromom, otrok s posebnimi potrebami

## **ABSTRACT**

**Introduction:** Down syndrome was named after Dr. Langdon Down who recognised its features as early as in 1866. It is a disorder in the genetic code, more specifically on chromosome 21, which is why it is also referred to as trisomy 21. Every cell of people with this disorder includes 47 chromosomes instead of the usual 46. They have characteristic physical features and often demonstrate mental retardation. However, not all persons have the same characteristics and the same level of the latter. The differences between them are as big as those between other people. Today, they are being integrated into the society in all respects and have been granted constitutional rights. Our aim was to investigate the role of the family in the development of a child with Down syndrome.

**Methodology:** Our research was based on qualitative research method. We have conducted a semi-structured interview with the parents of a child with Down syndrome. On the basis of this interview and with regard to the research questions we then determined the codes and put them into categories, which we then compared with the professional literature.

**Results:** A thirteen-year old girl has physical signs typical of people with Down syndrome. Today, she is included into a special customized program within a school with special curriculum, because she was not able to follow the regular curriculum. This indicates a serious disturbance in the cognitive domain. Compared to her equals, she demonstrates excellent motoric abilities, which her parents are strongly encouraging. She has never had any special health issues. Her family has a positive attitude towards the situation. They have accepted her as she is, and they always provide her with full support to enable her to live as independently as possible.

**Discussion and conclusion:** We have concluded that the family is of crucial importance in the development of a child with Down syndrome. In addition to the care for the child and their continued effort, the family should also regularly include the child into the activities necessary for the child's successful development. They should work with experts in various disciplines and follow their recommendations at home as well. In addition, they must ensure that family members are closely linked and adopt a positive attitude, since family atmosphere is of crucial importance in the development of children with special needs.

**Key words:** Down syndrome, treatment of children with Down syndrome, child with special needs