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Children with Down syndrome and health management information system

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ABSTRACT

This study examines the use of electronic systems to improve health care for people with Down syndrome in the midst of fast-paced advancements in information technology. It notes that current systems often fail to fully recognize the intellectual abilities of individuals with Down syndrome, especially concerning their health needs. The research highlights the importance of health management information systems (HMIS) in managing patient information effectively. It suggests creating detailed databases that include essential details like diagnoses, analyses, reports, and specific patient information. The goal is to address ongoing health issues and ensure that health services are efficient and uphold high professional standards. This study points out the value of using existing health data for immediate analysis to move health services toward a more professional and electronic future. This work adds to the discussion on technology-driven health management, showing how information systems can be used to improve healthcare outcomes.

1. Introduction

Health information systems are becoming increasingly important to measure and improve the quality and coverage of health services (Campbell, 1997). Today, systems directly affect how managers decide. Responsibility for information systems cannot be delegated to technical decision-makers (Lippeveld et al., 2000). Managers in each sector, as well as in the health sector, should have more information available. Management means coordinating and directing the planning elements; uncertainty is the most difficult situation managers frequently encounter in practice. Sometimes, there was not enough information to make important decisions. Since information is the main source from which to make significant estimates, the need for a qualitative information system in health is increasingly growing. Every Decision-making process produces a final choice (Reason, 2000) that may or may not prompt action. Research and studies conclude that leaders' lack of access to real data and time when making important patient decisions is a challenge we face in primary care facilities. Sometimes, this issue has had an impact on future planning and policies of countries, even for children with the syndrome (Mosadeghrad, 2014). A health management information system is a system that facilitates the collection and reporting of information on different patients, helping health management staff to accurately monitor the condition of patients full-time and in the right place. This system enables data collection, analysis, and case management for interventions and other critical issues for patients. This system also provides online access to data and statistical reports to review information for important decisions for patients (children with the syndrome) in the future (WHO, 2015; Katja, 1988).

The novelty of this paper lies in its comprehensive exploration of the evolving role of Health Information Systems (HIS) and their impact on decision-making within the healthcare sector. It emphasizes the increasing importance of HIS in measuring and enhancing the quality and coverage of health services. The paper recognizes the dynamic nature of decision-making in health management, highlighting that responsibility for information systems cannot be solely delegated to technical decision-makers. It introduces the notion that managers across sectors, particularly in healthcare, require more accessible and relevant information. The paper underscores the challenge of decision-making in the face of uncertainty and the need for a qualitative information system in health. Notably, it

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addresses primary care facilities' specific challenges, citing real-world examples of how the lack of timely and accurate data can impact patient decision-making, even influencing future planning and policies. Identifying Health Management Information System (HMIS) components, such as financial management, human resources, logistics, supply management, physical asset management, and integrated health service management, contributes to a holistic understanding of the HIS structure.

The World Health Organization has identified the HIS as a priority. In contrast, it has been identified as a weakness when we do not have support from one system, and efforts to strengthen national information systems have often produced slight improvement and sometimes caused problems. Worse (WHO, 2000). Based on experience and research, IHMS cannot be fully integrated into a single entity in each environment. Therefore, it also consists of (a) a financial management information system (FMIS), (b) a human resource management information system (HRMIS), (c) a logistics and supply management information system (LMIS), (d) a physical asset management information system (PAMIS) and (e) integrated health service management information system (HSMIS) (Mbaka and Namada, 2019). The Health Information Management System is this structure and collects information from all subsystems to serve as an efficient HMIS. The HMIS is essential for a company's policy-making because it is based on arguments and informed decision-making when planning, implementing, and evaluating health programs; thus, it enables the proper use of resources at all health system levels (Stucki et al., 2017).

To enhance the robustness and credibility of this study, a benchmarking analysis will be incorporated to systematically evaluate the obtained results compared to existing findings within the field. Benchmarking is a crucial aspect of research as it provides a means to assess the performance, efficacy, and uniqueness of the proposed HMIS for individuals with Down syndrome. By benchmarking against established works in the literature, we aim to gauge the novelty of our approach, identify potential areas for improvement, and contribute valuable insights to the broader academic discourse. This comparative analysis will validate our results' reliability and offer a comprehensive perspective on the effectiveness of the proposed system in relation to similar endeavors. The benchmarking process will involve a meticulous review of pertinent literature, emphasizing key metrics, methodologies, and outcomes, ensuring that our study aligns with the current state-of-the-art in the domain.

2. Children with Down syndrome

Down syndrome is the most common genetic disorder. It is caused by the excess of one chromosome or part of the chromosome in the cell nucleus. This disorder prevents the normal physical and mental development of the child. Although some genetic mental retardation syndromes have well-described behavioral features, comparative studies have not yet assessed the relative uniqueness of these so-called phenotypes (Dykens and Kasari, 1997). Since there are three copies of the 21st chromosome, trisomy twenty-one is also known. The syndrome affects all racial groups and can occur in any family regardless of other factors. As much as it is impossible to prevent the onset of the Syndrome, it is possible to detect before birth whether an unborn child is ill and to prepare in a timely manner for all the challenges that come with the current birth of a child. Children with Down syndrome have multiple malformations, medical conditions, and cognitive impairment because of the presence of extra genetic material from chromosome twenty-one (Schieve et al., 2009). Children need special attention, various treatments and therapies, and tailored teaching methods and strategies. People with Down Syndrome have physical characteristics such as a wide neck, oblique eye position, round head, and short fists. Children with Down syndrome have sensory integrative dysfunction as a result of limited sensory experience from a lack of normal motor control (Uyanik et al., 2003). Also, besides the visible characteristics, they are accompanied by numerous health problems and mental retardation. People with Down syndrome must be included in early intervention programs to maximize their potential and opportunities (Van Den Driessen Mareeuw et al., 2020). Down syndrome is a choking chromosome that results from a delay in physical, intellectual, and linguistic development. This is the most common chromosomal disorder associated with mental retardation. People with the syndrome have a characteristic physical appearance. The Down syndrome is identified as a chromosomal abnormality. With advances in molecular biology, it has been found that people with the syndrome have forty-seven chromosomes in each cell instead of 46. This extra chromosome, partially or completely chromosome twenty-one, results in the characteristics associated with Down syndrome (Butler et al., 2016). Usually, the diagnosis of Down syndrome is suspected immediately after birth, thanks to the physical appearance of the baby, although these physical characteristics can be seen in a large population. Therefore, if there is doubt about the syndrome, a chromosome test should be done immediately after the baby's birth. Think that 1 in 800 to 1100 births result in a baby with Down syndrome. Studies have shown that more males than females develop chromosomal disorders. Or mother or father can carry extra chromosomes. In 70% to 80% of cases, mothers carry extra chromosomes. 80% of children with Down syndrome are born of a midwife under the age of 35, but the rate of divorce is higher for women over the age of 40. At age 40, the chance of having a baby with Down syndrome is approximately 1 in 110 births, while at age 45, the risk becomes greater than 1 in 35 births. Women with Down syndrome have children, but the chance of having children with Down syndrome is 50%

(Tsou et al., 2020). The mortality of children with the Syndrome is decreasing. With advances in science for the medical treatment of persons with Down syndrome, today, I think the age of people with Down syndrome has reached fifty-five, and there are even more cases (Little, 2015). The number of people affected with Down syndrome in Kosovo recorded totaling 719 people with an incidence/accident of birth from 18 to 35 babies per year, and the number of mortality in recent years amounts to 19 deaths. This results from a lack of medical treatment, such as a lack of heart surgery. Health in children with Down syndrome is poor due to improper development of specific organs as a result of processes similar to premature maturation or a disordered immune (Roizen and Patterson, 2003). Fig. 1 depicts a visual representation related to Down syndrome in the medical field. It is an illustration showing specific characteristics or medical aspects of individuals with Down syndrome.

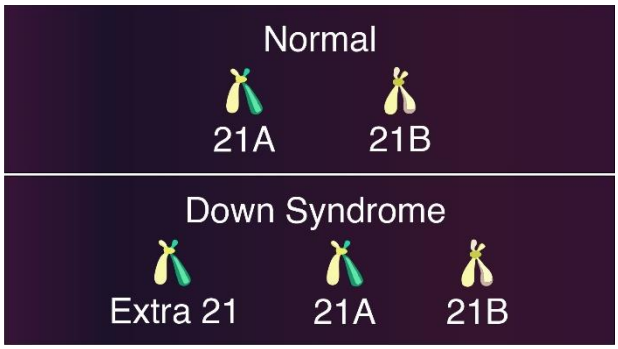

Fig. 1: Down syndrome (Ijezie et al., 2023)

The diagnosis of Down syndrome is usually suspected immediately after birth due to the baby's physical appearance. Therefore, if Down syndrome is suspected, a chromosome test should be performed immediately after the baby is born. Screening tests during pregnancy include a combined test during the first trimester and an integrated screening test. Clinicians should ensure a balanced approach rather than their personal opinions, give current printed materials, and offer access to other families who have children with Down syndrome and support organizations if locally available. It is important that clinicians be cognizant of the realities and possibilities for healthy, productive lives of people with Down syndrome in society (Skotko et al., 2009). It should also be recommended to private and public companies to support these children first by offering them the opportunity to intern at their companies so that they can socialize and be on the move and then hire them for the jobs they are trained for Bonaccio et al. (2020). These children are part of society, and society must do more for this category. First, the infrastructure should be established to create more therapeutic treatment centers such as:

a) Exercises for relaxation and extension of muscles;
b) Exercises to maintain and increase muscle strength;
c) Coordination exercises;
d) Coordination and balance exercises;
e) Kinesiology/motor education.

2.1. HMIS

Information Technology is a formatted computer system that can collect, supply, and process data from various sources to provide the necessary information to management during the decision-making process (Berisha-Shaqiri, 2014). The organization of the management's computing system should be built to adapt to the structure of governance system organization at different hierarchical levels and computer systems based on electronic data processing. The management information system supports decision-making based on systematic methods and analysis. Based on this, software has been developed to evaluate alternatives in the preparatory phase of the decision-making process. These systems are known as Decision Support Systems (DSS). To make a good decision in an assist, we use management information systems, which provide us with support decisions quickly and opportunities for analytical assessments. Sometimes, the information is not enough to make crucial decisions. Given that information is the primary source for making critical evaluations, the need for a quality healthcare system in health is growing even more (Fritz, 2017). The HMIS is a specialized information-gathering system that supports planning, management, and decision-making in environments and health organizations. The HMIS encompasses processes to ensure data quality, management of data processing, reporting, analysis, and the use of information related to individuals and families. This includes data on vaccinations, family planning, maternal and child health, HIV treatment and support, and other health services. The HMIS makes this information accessible to all individuals in a country, similar to how a family file works (Kasambara et al., 2017). Health informatics systems today directly influence the understanding of health priorities in country strategies, as well as global health policies through a cross-national comparative overview of key issues, concepts, and theories related to planning, assessment, financing, organization of health systems around the world, management and reform of personal care as well as health-oriented systems of population, leadership, and global health actors. From the research and studies, it is concluded that the lack of access to real and timely data from the leaders at the moment of making important decisions for the patients is a challenge facing the healthcare centers. Sometimes, this issue has also affected the countries' future planning and national policies. Even for Down syndrome Children, a little health informatics system would facilitate the introduction of adequate policies for better care of these categories (Mosadeghrad, 2014). The HIS needs to be developed continuously to keep up with the contemporary trends of development to apply the best practices in the world to master modern health and to understand and

articulate different approaches to moral, ethical, and bio-ethical. The IT management system aims to gather, unify, and analyze all data and health information and use it to compile effective and contemporary strategies of communication and health information with the ultimate aim of improving the quality of health care, reflected in the growth and sustainable improvement of the health outcomes and indicators of a country's population. So, get to know the basics of data management and the processes and techniques for overcoming various situations (Sharon, 2017). The HMIS is a system that facilitates the collection and reporting of various patient information, helping health management staff to accurately monitor the complete condition of patients at the right time and place. This system makes it possible to collect data and analyze and manage cases of interventions and other important issues for patients. This system also provides online access to data as well as provides statistical reports to review information for making important decisions for future patients (Poon and d'Oiron, 2018). Therefore, the purpose of this paper is to present the importance of IT management systems to manage and use patient information in order to have a database with sufficient information about diagnoses, analyses, reports, and other forms of specific patient data to use these data for further analysis to ensure that health services are as professional as possible (Dash et al., 2019).

2.2. Benefits from HIS

The HIS always intends to increase the efficiency in managing the disease and the patients, making it easier to decide on the patient's condition and take further measures. Fig. 2 represents the flow of data within the HMIS of a country, as outlined by WHO (2004). It likely shows how information is collected, processed, and used within the healthcare system

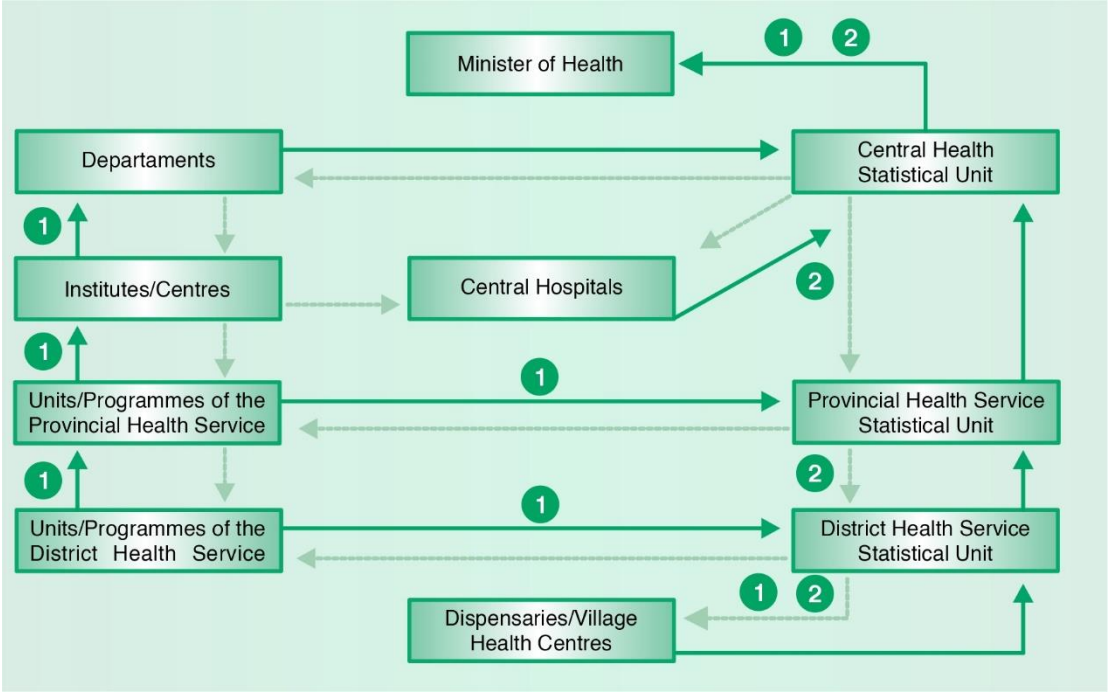

Fig. 2: Data flow for the HMIS of the country (WHO, 2004)

At the moment, we have data on children with the syndrome. The doctor has a lot of easy diagnoses and treatments because he has a database of previous treatments (Williams et al., 2019). What are the biggest benefits of having a health informatics system for Syndrome children? Data Analysis: This HIS continuously produces information. Data and information from the HIS help collect, compile, and analyze health data to help manage the health of children with the syndrome, helping reduce healthcare costs. Firstly, analyzing these data on health care can improve the care of patients with Down syndrome (Fransen et al., 2019). Collaborative care: Patients or children with the Syndrome often need treatments from different healthcare providers. The HIS provides the information needed for the urgent needs of these patients. Cost Control: The use of digital networks to exchange data and information on health care creates efficiency and cost savings. Regional markets use health information exchanges to share data, and healthcare providers reduce costs through these communications and information exchanges. In other words, information technology systems help to exchange information and help hospital managers increase efficiency through electronic communication (Payne et al., 2019). Use of information technology: Large-scale data collection and modification enabled individuals with Down syndrome to function in a consistent adaptation to society's requirements in their status values as a new application that controls their lives in the morphological parameters of abandoned children (Fritz, 2017). Health Management of Children with Down syndrome and Others: HIS can unite patient

data and analyze and identify growth or decreasing tendencies for these patients. Technology also works where management systems support decisions by using large data to help diagnose individual patients and treat them (Memon et al., 2017).

A typical example of a health IT system is Epic Systems Corporation, which provides electronic health records (EHR) and other software solutions to healthcare organizations worldwide. This system was founded in 1979 and is known for its comprehensive and integrated EHR software, used by various healthcare settings, including hospitals, clinics, and health systems. The purpose of this system is to collect and organize patient health information, including medical history, diagnoses, medications, treatment plans, immunization records, lab results, and more. It provides a centralized database accessible to authorized healthcare providers.

In 2015, the adoption of electronic health records doubled in seven years. About 96% of hospitals and 87% of private clinics used electronic registration. Here are some of the programs used in the US:

Medical Practice Management (MPM), this software helps manage various administrative and clinical management aspects. The MPM program aims to run things in an automated way. MPM is focused on managing patient flow and general office documentation.

Electronic Healthcare Records/Electronic Medical Records: this software focuses on storing and documenting patient medical information. There is no need for doctors to write on paper; they should fill in the information on the computer. The problem with the EMR was that patient records could only be viewed in one office, so if a patient was transferred to another clinic, their information could not be transferred. For this reason, Electronic Healthcare Records (EHR) were created to share information with other departments. Fig. 3 illustrates the concept of Electronic Health Records (EHR) or Electronic Medical Records (EMR) systems used for storing and managing patient medical information electronically. It shows how these systems eliminate the need for paper records and enhance information sharing among healthcare providers.

Fig. 3: Electronic healthcare records/electronic medical records

The adaptation of this software in Kosovo to organize and manage data for children with Down syndrome would be a great achievement. In Kosovo, patients are still recorded in the registration book, so we think that this form is now obsolete

3. Methodology

The Information System Management collects data on problems in general, based on the approach of children with Down Syndrome distributed across families. The study of the paper is confirmed by the type of problem faced by health care with the request of the questionnaire, whether they had a family doctor, and how many times they have faced emergency requests. In this study, we used quantitative methods based on data extracted from a questionnaire. The deductive approach was used in this study to combine our methodological approach with a theoretical basis. The entity sample defines the population of children with Down syndrome (31) and healthy children (31) in Pristina, Prizren, Ferizaj, and Mitrovica; 62 children will be examined.

4. Analyses of case studies

Characteristics of children with Down syndrome and Down syndrome in morphological, physiological, biomechanical, and motor space Derivation of some anthropometric status values of children with Down syndrome; Verification of statistically significant differences between the group of children with Down syndrome and the community of healthy children in the morphological space; Verification of statistically significant changes in physiological parameters between the group of children with Down syndrome and the community of healthy children before, during and after submaximal physical activity; Verification of statistically significant differences in biomechanical and motor parameters between children with Down syndrome and the community of healthy children; Verification of the latent structure of space: morphological, physiological and motor, examined. Table 1 provides the height statistics for both healthy children and children with Down syndrome. For healthy children, the sample size is 31, with heights ranging from 144.0 to 167.0 cm and a mean height of 159.355 cm. The standard deviation is 4.1837, and the variance is 17.503. On the other hand, children with Down syndrome also have a sample size of 31, with heights ranging from 125.0 to 162.3 cm and a mean height of 146.284 cm. The standard deviation is 10.0383, and the variance is 100.768. The descriptive statistics in Table 1 help to compare the height measurements between the two groups, providing insights into any potential differences in height distribution. Table 2 presents the head circumference, biomechanical, and motor parameters among children with Down syndrome. It provides statistics on the minimum, maximum, mean, standard deviation, and variance for head circumference measurements in both healthy children and children with Down syndrome. The comparison shows the differences in these measurements between the two groups. Table 3, on

the other hand, shows the T-test results for head circumference between healthy children and children with Down syndrome. It includes the t-value, degrees of freedom, significance level (two-tailed), mean difference, and 95% confidence interval of the difference. The T-test helps determine if there are statistically significant differences in head circumference measurements between the two groups.

Table 1: Community of children with Down syndrome

Height	N	Minimum	Maximum	Mean		Std. deviation	Variance
	Statistic	Statistic	Statistic	Statistic	Std. error	Statistic	Statistic
Healthy children	31	144.0	167.0	159.355	.7514	4.1837	17.503
Children with Down syndrome	31	125.0	162.3	146.284	1.8029	10.0383	100.768
Valid N (listwise)	31						

Table 2: Head circumference biomechanical and motor parameters among children

Head circumference	N	Minimum	Maximum	Mean		Std. deviation	Variance
	Statistic	Statistic	Statistic	Statistic	Std. error	Statistic	Statistic
Healthy children	31	44.0	59.0	53.226	.5158	2.8718	8.247
Children with Down syndrome	31	47.0	57.0	50.548	.3611	2.0103	4.041
Valid N (listwise)	31						

Table 3: T-test Head circumference (Test value = 0)

	t	df	Sig. (2-tailed)	Mean difference	95% confidence interval of the difference	
					Lower	Upper
Healthy children	103.192	30	.000	53.2258	52.172	54.279
Children with Down syndrome	140.001	30	.000	50.5484	49.811	51.286

In Table 4, descriptive parameters and differences between the two groups in anthropometric variables are provided. The body weight of normal children is higher (55.22 kg, SD+-5.59) compared to children with Down syndrome (49.03 kg, SD+-14.21). Similarly, in other anthropometric variables, normal children exhibit higher values than those with Down syndrome.

Table 4: T-test results for weight and leg length

Variables		Mean	Std. deviation	t	p-value
Weight	Healthy children	55.22	5.59	2.76	0.007
	Children with Down syndrome	49.03	14.21	2.34	0.024
Leg length	Healthy children	78.74	8.24	-2.5	0.016
	Children with Down syndrome	74.76	4.52	-2.82	0.006

In Table 5, the results for blood pressure and heart rate before and after physical exertion are presented. Before physical exertion, normal children have lower values in heart rate (80.12 bpm, SD+-10.93) compared to children with Down syndrome (85.16 bpm, SD+-12.56). Regarding blood pressure, normal children exhibit lower systolic pressure (111.18 mmHg, SD+-10.88) than children with Down syndrome (121.94 mmHg, SD+-21.69). However, for diastolic pressure, the values are identical (75.78 mmHg, SD+-8.45 for normal children and 75.80 mmHg, SD+-13.80 for children with Down syndrome).

Table 5: T-test results for heart rate (HR), systolic (Sistol), and diastolic (Diast) measures

Variables		Mean	Std. deviation	t	p-value
HR	Healthy children	80.12	10.93	-1.92	.058
	Children with Down syndrome	85.16	12.56	-1.86	.067
Sistol	Healthy children	111.18	10.88	-2.97	.004
	Children with Down syndrome	121.94	21.69	-2.60	.013
Diast	Healthy children	75.78	8.45	-.008	.994
	Children with Down syndrome	75.80	13.80	-.007	.994

The analysis of the results clearly shows the physiological differences between healthy children and children with Down syndrome. The analysis aimed to compare some anthropometric parameters of children with SD and those with normal development. The obtained results have proved that in anthropometric parameters, children with normal development have higher values than children with SD. The load with the only difference in diastolic pressure is higher in normal children. The reason for such behavior can be seen in the short time of the load (only one minute of running in place), where the cardiovascular system is not provoked enough.

Any HIS that highlights these physiological and organic changes would be welcome to help these children be equal in society at work and in life. According to the studies to manage the information system for children with Down syndrome, we have used good practices of services through the new application in support of efficient management for integrating persons with DS (Down syndrome) capacity (E-Fajar et al., 2022).

5. Conclusions

Conclusions from the research concluded that the Health Ministry in Kosovo should make every effort to develop an appropriate infrastructure for the management of information for children with syndrome by providing and placing a high priority on implementing the health information management system for the health sector in Kosovo. The purpose of this paper is to present the importance of systems management information to manage and exploit information about patients in order to have a base of data with information sufficient regarding diagnoses, analyses, reports, and other forms of specific data for patients to utilize this data for further analysis that health services be as professional. Society and institutions should be the most supportive of the integration of persons affected by Down syndrome to be an equal part of society. The tendency of health system development for children with special needs reduces the impacts of particular problems by the inaccuracy of information data. Therefore, information is important to monitor and report problem-solving (Islam et al., 2018). Children with Down syndrome can and should be enrolled in regular school programs. Social acceptance will majorly impact their self-awareness, self-esteem, and identity-building. Students with the Syndrome benefit from staying in an environment where they are properly spoken to and communicated with and use the example of children without difficulty, especially in mastering skills such as reading and writing. Many positive changes have taken place in the 20th century in the lives of children and adults with Down syndrome: Life has quadrupled, society is much more aware of educational programs, abandoned children are more often adopted, and children are increasingly integrated into mainstream education. There are organized special communities for adults, and they are provided with further education, training, and employment opportunities (Bonaccio et al., 2020).

Compliance with ethical standards

Ethical consideration

This study was conducted in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study or their legal guardians. The confidentiality and privacy of participants were strictly maintained, and all data were anonymized. The research protocol was reviewed and approved by the ethics committee of the University for Business and Technology in Pristina, Kosovo. Special care was taken to ensure that the research methods and data collection processes were appropriate and sensitive to the needs of children with Down syndrome.

Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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