JOURNAL OF EDUCATIONAL SCIENCES THEORY AND PRACTICE Vol. 20, No 1, 2025

Received: 30.06.2025
doi:
UDK 616-056.7:575.224.232.3]:373.3(497.7
Revised: 27.08.2025
Accepted: 30.08.2025

# SUPPORT FOR CHILDREN WITH DOWN SYNDROME IN PRIMARY SCHOOL

**Jadranka Runcheva[1], Bojana Perić Prkosovački [2] Simona Stojanovska[3]**

[1]Faculty of Educational Sciences, Goce Delcev University Stip, R.N.Macedonia
jadranka.runceva@ugd.edu.mk
[2]Faculty of Medicine, University of Novi Sad, Serbia
bojana.peric-prkosovacki@mf.uns.ac.rs
[3] Graduate Pedagogue at Faculty of educational Sciences, Goce Delcev University Stip, R.N.Macedonia simona.141925@student.ugd.edu.mk

## Abstract

Inclusion in the educational process is a concept focused on providing equal opportunities for all students, regardless of their individual abilities, background, or needs. The primary goal of inclusive education is to create a school environment in which every student can develop and thrive, regardless of their specific needs or challenges. In order to ensure equal access to the educational process and to improve the academic and social outcomes of these children, it is important to implement specialized strategies and support methods in primary education. The application of these strategies and resources not only enhances the academic success of children with Down syndrome but also promotes their inclusion and social integration within the school environment. To achieve the best results, effective communication and collaboration between teachers, parents, and specialists are of crucial importance.

**Key words:** Inclusion, Children with Down Syndrome, Macedonia.

## Introduction

Inclusion in the educational process is a concept focused on ensuring equal opportunities for all students, regardless of their individual abilities, background, or needs. The primary goal of inclusive education is to create a school environment in which every student can develop and thrive, regardless of their specific needs or challenges. (UNESCO, 2025; UNESCO, n.d.).

Според WHO *(Guideline for Medical Management of Children with Down Syndrome, 2015, p.13)*, „*Down syndrome is a genetic condition caused by the presence of all or part of a third copy of chromosome 21, which is why it is also known as trisomy 21. It is associated with physical growth delays, intellectual disability and characteristic facial features*.“ It was officially named after John Langdon Down, who provided its clinical description in 1866. In 1959, Lejeune and colleagues confirmed that Down syndrome was linked to a chromosomal abnormality. Even decades after this discovery, outdated terms like "mongolism" are still wrongly used, and many individuals with Down syndrome continue to be institutionalized. Health complications related to the syndrome are often inadequately addressed, leading to early mortality in infancy or young adulthood. Despite these challenges, advocacy groups rooted in the community have pushed for better healthcare and research to support people with Down syndrome (Mégarbané et al., 2009). These efforts, alongside advances in medical knowledge and treatment, have contributed to a significant increase in life expectancy — more than doubling since the 1980s, from around 25 years to approximately 60 years today (Global Down Syndrome Foundation, 2019).

During early development, the presence of an extra chromosome affects the way a baby's body and brain form, which may lead to both intellectual and physical difficulties.

"*Children with Down syndrome often experience developmental delays, including slower progress in speech compared to their peers. Characteristic physical traits of Down syndrome are typically visible at birth and may become more noticeable as the child grows. These features often include: A flat facial profile, particularly around the nasal bridge, Upward-slanting, almond-shaped eyes, A tongue that frequently protrudes from the mouth. Additional physical characteristics may involve: A short neck, Smaller-sized ears, hands, and feet, A single crease across the palm, Short or curved pinky fingers, Low muscle tone and flexible joints, Below-average height. In addition to these traits, individuals with Down syndrome may face health issues such as: Congenital heart conditions, Hearing impairments, Obstructive sleep apnea*" (CDC, 2023).

According to UCSF Health, in the United States, Down syndrome occurs in approximately 1 in 1,000 live births, regardless of ethnicity, culture, socioeconomic status, or geographic region. The risk increases with maternal age—about 1 in 1,400 for women under the age of 25, 1 in 350 at age 35, and 1 in 100 at age 40 (UCSF Health).

## Inclusion of Children with Down Syndrome

In children with Down syndrome, speech and language abilities can vary significantly from one child to another, but overall, their development is slower compared to peers with typical development. The first words may emerge over a wide time range—from approximately one to five years of age. Many children use signs or pictures to communicate even before they can speak, sometimes as early as 10–12 months. (Boston Children's Hospital, Community Inclusion). The guidelines of the National Down Syndrome Society and Down Syndrome Education International (2021) recommend initiating speech therapy support from the earliest age and continuing throughout the preschool period. Basil and Herreras (2010) note that children with Down syndrome often show weaknesses in verbal short-term memory, while their visual short-term memory remains relatively preserved. This strength in visual processing can be leveraged as a compensatory strategy, contributing to improved comprehension of written materials.

De Graaf, Van Hove, and Haveman (2013) found that students with Down syndrome achieve better outcomes in speech development and academic skills—particularly in reading—when educated in inclusive classrooms alongside peers with typical development. Although their learning pace is slower, they demonstrate strong motivation and the ability to make progress. Due to their pronounced visual orientation, they process information more effectively when it is presented through pictures and illustrations, and teaching strategies that combine visual and multisensory approaches have proven particularly effective (Positive Action Staff, 2023). A study published in Psychological Science included 670 children from Ohio, more than half of whom had a disability, including Down syndrome. After one academic year, children who were in classrooms with peers possessing highly developed language skills achieved nearly the same results as students without disabilities, whereas those in environments with peers with poorly developed language skills lagged significantly behind. The difference in progress was approximately 40% in favor of the first group (Disability Scoop, 2014).

Research indicates that most children with Down syndrome develop appropriate social skills and behaviors, as well as the ability to establish interpersonal relationships. They often demonstrate empathy, warmth, and a willingness to help or please others, which contributes to building and maintaining positive relationships within the family, with friends, and in the broader community. However, this heightened social sensitivity can also present challenges—strong reactivity to negative emotions, such as anger, sadness, fear, or anxiety, can cause significant stress. If such conditions persist over time, they may lead to anxiety, depression, or increased obsessive-compulsive behaviors. These emotional reactions are not always triggered by close individuals but can also arise from interactions with strangers or even completely incidental encounters in public spaces (Adult Down Syndrome Center; NDSS & DSEI, 2021).

## People with Down Syndrome in Macedonia

We aimed to determine how many children with Down syndrome are included in regular schools through inclusive education, but such data we could not be found. The only available figures on children with Down syndrome come from the State Statistical Office, which reports on the number of individuals with Down syndrome in institutions for persons with intellectual and physical disabilities.According to data from the State Statistical Office, the number of people with Down syndrome included in institutions for individuals with intellectual and/or physical disabilities in Macedonia is relatively small compared to other categories of disability. Between 2016 and 2019, no individuals with Down syndrome were recorded in these institutions, while in 2020 there were 2 registered cases, and in 2021 and 2022 – 4 cases each year. These figures suggest that some individuals with Down syndrome may be included in regular schools or covered by other forms of support outside institutional care. However, such low numbers may also be the result of underreporting or differing criteria for record-keeping. Compared to other categories – for example, severe intellectual disability (133 individuals in 2022) or people with multiple disabilities (44 individuals in 2022) – the number of individuals with Down syndrome is significantly lower. This raises questions about the need for improved record-keeping, as well as the development of community-based support and inclusion programs within the local community and the educational system.

Table 1. Persons with Disabilities in Macedonia Included in Institutions for Individuals with Intellectual and Physical Disabilities

| | | | 2016 | 2017 | 2018 | 2019 | 2020 | 2021 | 2022 |
|---|---|---|---|---|---|---|---|---|---|
| Institutions for persons with intellectual, mental and physical disabilities | Type of disability | Moderate mental disability | 88 | 73 | 72 | 85 | 52 | 44 | 43 |
| | | Severe mental disability | 201 | 207 | 202 | 197 | 192 | 174 | 133 |
| | | Profound mental disability | 10 | 8 | 8 | 7 | 7 | 7 | 4 |
| | | Hearing loss | / | / | / | / | / | / | / |
| | | Damaged species | / | / | / | / | / | / | / |
| | | Voice, speech and language disorders | / | / | / | / | / | / | / |
| | | Physically disabled | 51 | 40 | 39 | 35 | 17 | 17 | 17 |
| | | Autistic people | / | / | / | / | 3 | 8 | 8 |
| | | People with Down syndrome | / | / | / | / | 2 | 4 | 4 |
| | | Chronically ill persons | / | / | / | / | / | / | / |
| | | Persons with combined disabilities | 7 | 21 | 22 | 6 | 45 | 44 | 44 |

Source: State Statistical Office. Social Protection of Children, Youth and Adults (2016–2022). Available at: https://www.stat.gov.mk

## Methods

A study was conducted between August and October 2024 to gain a deeper understanding of the personal experiences and perspectives of parents of children with Down syndrome. Through their narratives, an effort was made to shed light on key aspects of the lives, upbringing, education, and support of these children in the context of mainstream primary education.

The primary research method applied was a semi-structured interview, consisting of six thematic sections and several open-ended questions. The topics covered were: (1) general information about the child, (2) interests and favorite activities, (3) family life and social aspects, (4) The education and development of children with Down syndrome (5) support and resources, and (6) future, hopes, and recommendations.

The interviews were conducted via email, with questions organized according to thematic sections. This format allowed participants to respond at their convenience, providing the opportunity for more detailed and thoughtful answers.

Four parents of children with Down syndrome from Macedonia participated in the study. All participants chose to remain anonymous. The data obtained from the interviews were processed and presented in full, with strict adherence to confidentiality and privacy. The ultimate aim of the research was to provide a deeper and more personal understanding of the daily lives of families with a child with Down syndrome—their challenges, needs, hopes, and experiences with the educational system—thereby contributing to the development of more effective and sensitive inclusive practices.

## Results and Discussion

### Analysis of general information about children with Down syndrome

As part of the survey, parents were asked to provide a brief description of their child: their age, interests, activities, and personality traits. This question allowed for initial insight into the individual characteristics of children with Down syndrome, their affinities, and daily habits.

The diversity in age (one child is 7 years old, one child is 8 years old, one is 12 and one is 14 years old (two boys, two girls) from different cities in Macedonia) gives us the opportunity to observe the experiences of different developmental stages – from early childhood to adolescence.

As for character traits, all parents describe their children with positive and emotionally colored words. The most frequently mentioned are: curiosity (7-year-old girl, 8-year-old girl), calm and kind character (14-year-old boy), energy and liveliness (12-year-old boy), sociability and connection with the family (all four children).

Children with Down syndrome are curious and actively involved in family and community life, as demonstrated by their interests and activities.

### Interests and favorite activities

These children are similar to their peers, which is important for an inclusive approach in education and society. Each child shows that they have rich worlds and interests:

- *Art and creativity* – both girls show interest; they enjoy drawing, painting, and creating pictures from natural materials.
- *Nature and physical activity* – the 7-year-old girl enjoys walks, collecting leaves, and exploring parks.
- *Love for animals* – shown by the 7-year-old girl and the 12-year-old boy.

- *Sports and family activities* – the 14-year-old boy enjoys football, sports competitions, birthday celebrations, and family vacations.
- *Technology and media* – both boys (aged 12 and 14) watch animations, YouTube, and play computer games.

### Family life and social aspects

A highly valuable and profound segment of the research, which reveals the emotional, logistical, and social reality of the families, is precisely the aspect of family life and social interactions. Parents of children with Down syndrome describe receiving the diagnosis as an emotionally intense and vulnerable moment in their lives. Emotions of shock, fear, and uncertainty were present, especially in the first days after the diagnosis was given. Parents use terms such as “shocked,” “afraid,” “upset,” and “confused,” indicating deep emotional distress and a sense of insecurity. The most common source of fear was the uncertainty about the future, as well as the lack of information about what Down syndrome actually means and what life would be like for their child. Parents point out that, after the initial shock, they developed a positive perspective and focused on their child’s abilities rather than limitations. They emphasize that the experience, although difficult, strengthened family bonds. They say they became stronger, more experienced, and more sensitive to their child’s needs.

- *Change in family dynamics* – Three parents describe adapting by **centering attention and activities around the child**, with the whole family actively involved. The parent of the 14-year-old boy provides a detailed account of the adaptation process, particularly in early childhood – coping with feeding, motor development, acquiring hygiene habits, as well as logistical and financial pressures.
- *Social aspects and inclusion* – **Two parents** speak about positive **peer relationships with their child**, noting participation in group games and activities, which indicates successful inclusion. In contrast, the other **two parents** observe challenges in social interactions; in one case, there is an extensive account of isolation, lack of support from relatives, logistical burdens, and financial stress, revealing the hidden side of the reality families face.
- *Family solidarity and adaptation* – Parents point out that although life has become more organized and more complex, they feel **more strongly connected as families**. They have developed a greater sense of responsibility, dedication, and empathy, while parents have acquired knowledge, patience, and resources they did not possess before.

### The education and development of children with Down syndrome

This part of the research is particularly significant, as it reveals the real and often invisible aspects of the education and development of children with Down syndrome, from the perspective of parents. The parents involved in the research described the challenges, achievements and personal strategies related to the educational development of their children with Down syndrome. The responses indicate significant differences in access, conditions and support, but also a common thread: the strong commitment of parents to provide the best possible conditions for learning.

- *Individualized approach as a key strategy* - Three parents emphasize that an individual approach, adapted to the interests and needs of the child, has proven to be the most effective model of support. All three children work either with special educators, special education teachers and therapists, or are included in individual education plan (IEP) programs. The importance of visual aids, practical teaching and multisensory approaches, which help children more easily master the teaching material, is particularly emphasized.
- *Different educational models: regular and special education* – Both boys attend special schools where they receive support from special education teachers and

specialist teams. Both girls are involved in inclusive education with support from specialists and extracurricular services. This suggests that there is no single model that fits all children – the choice often depends on the level of support available in the community, the individual developmental profile and the family circumstances.

- *Systemic barriers* - The deepest and most comprehensive testimony was given by the fourth parent (parent of a 14-year-old boy), who describes: Logistical and financial difficulties (distance to institutions, absence of full-day classes, insufficient state support). Interruption of work engagement due to lack of adequate care. Problems with teaching staff - some teachers, despite working with children with disabilities, lack empathy, knowledge or willingness to engage. Problems with inclusion after the COVID-19 pandemic, which further disrupted the child's psychosocial stability and daily routine.
- *Positive examples* - Despite the challenges, all parents cite positive examples of dedicated teachers, good practices, and moments of progress. The boy's parent describes a kindergarten teacher who accepted the child as her own, promoting inclusion among the children – an example of true inclusive practice in early childhood development.

### Support and resources

Parents emphasize that support from healthcare and professional institutions, as well as from specialized organizations, has played a crucial role in the process of adaptation, information sharing, and providing developmental opportunities for their children. The most frequently mentioned sources of support include: **healthcare institutions** – local health centers, pediatricians, specialists; organizations for individuals with Down syndrome or other special needs; support groups, seminars, and workshops; and **individual support from professionals** (such as the doctor mentioned by the fourth parent). Three respondents point to **structured institutional support** that helped them with information about the diagnosis, access to therapies, and participation in training and educational programs. Parents describe the support as “crucial,” “significant,” and “helpful,” emphasizing that it was particularly important in the initial period after the diagnosis, when they felt the most confused and uninformed.

Participation in workshops and support groups has not only contributed to a better understanding of the condition but has also enabled contact with other families going through similar challenges – creating a sense of community.

### Future, Hopes, and Recommendations

- *Desire for a happy and fulfilling life with more opportunities* – All parents express hope that their children will have a happy, fulfilling, and dignified life, with opportunities for development, education, socialization, and independence. This reflects deep parental dedication and love, as well as their concern about long-term support and inclusion for their children.

- *Fear of the future without parental care* – A particularly emphasized concern is the future of the child after the parents are no longer present. One parent explicitly highlights the need for a systemic solution for the care of people with disabilities in adulthood, which is one of the most common and profound fears of families.

- *Criticism and hope for improvement of the education system* – Parents hope for an increase in inclusiveness and the quality of the educational process – both in regular and special education.

- *Advice for other parents* – Accept the diagnosis from the earliest stage, focus on the child's strengths, create a supportive environment, network with other parents, and seek professional support without fear or shame.

## Conclusion

Supporting children with Down syndrome in primary school is a complex and multidimensional process that requires careful planning, adaptation, and continuous collaboration between teachers, specialists, and families. In order to ensure the full integration and progress of students with Down syndrome, it is important to apply various strategic approaches that will support their academic, social, and personal development.

In fact, the aim of the study was to provide an overview of Down syndrome at the primary school level, placing emphasis on the teacher–student relationship as a form of support for the learning process and social interactions of students with this disability.

Half of the students with Down syndrome are included in mainstream schools, although this is not the case for all (two students are in special schools). Children with Down syndrome, like other groups of children, receive a high level of support in school.

The research showed that children with Down syndrome, despite individual differences in age, interests, and developmental profiles, share common characteristics such as curiosity, emotionality, sociability, and a strong connection to their families. Their interests and activities are often similar to those of their peers without disabilities, which confirms the importance of an inclusive approach in education.

Parental testimonies reveal that the path from diagnosis to acceptance is emotionally intense, but over time leads to strengthened family bonds, increased empathy, and commitment. Experiences vary—from positive examples of inclusion and teacher support to serious systemic barriers such as insufficient institutional assistance, financial and logistical difficulties, and a lack of trained staff.

Particularly noteworthy is the importance of an individualized approach, tailored to the needs and interests of the child, as well as the role of professional and institutional support in the early stages after diagnosis. Parents express hope for a happy and fulfilling future for their children, but also concern for the period after they are no longer able to care for them, pointing to the need for long-term systemic solutions for support and care.

These findings highlight the need to improve inclusive policies, strengthen support resources, and provide educational and social environments in which children with Down syndrome can fully develop their potential.

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