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A child with Down syndrome - Challenge for families, kindergartens and schools

Marina Duranovic ^{a*}, University of Zagreb, Croatia

Irena Klasnic ^b, Juraj Habelić Primary School, Velika Gorica, Croatia

Valentina Opic ^c, Open University Novska, Novska, Croatia

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Abstract

Every day, the number of children born with disabilities is increasing. One of the many disabilities is Down's syndrome, which occurs on average in one of 650 infants. For a child born with this disability, it is much more difficult to normally grow, develop and function in everyday life. In the past, children born with Down syndrome were neglected, and their education was not paid almost any attention. Today, there are significant changes in social awareness related to rights and needs of children with Down syndrome. Early intervention programs that are being developed in order to mitigate problems of children with disabilities are becoming much better, and the number of therapeutic methods is increasing. There are a number of institutions and organizations which provide assistance and support to the parents of children with Down syndrome. To encourage their overall development and enable easier and more efficient functioning in society, children with Down syndrome are being integrated into pre-school and school facilities. The aim of this work is to further sensitize the public to problems and needs of this very vulnerable population of children and show examples of successful integration of children with Down syndrome in kindergarten and elementary schools.

Keywords: a child with Down syndrome; family; school; educator; teacher; early intervention programs

*ADDRESS FOR CORRESPONDENCE: **Marina Duranovic**, University of Zagreb, Croatia.
E-Mail Address: marina.duranovic@kif.hr / Tel: +385 01 / 3658-666

1. Who are children with Down syndrome?

Down syndrome is the most common genetic disorder that occurs due to excess of one chromosome or part of a chromosome in the nucleus of the cell. The disorder prevents normal physical and mental development of the child. Down syndrome causes erroneous classification of chromosomes during cell division of gametes so the cells have an excess of a whole or a part of one chromosome (Kocijan, Dosen, Folnegovic-Smalc & Kozaric-KovaCic, 2000; Vukovic, Vrbic, Pucko & Marcus, 2008). The reason for such wrong cell division is random and is usually not hereditary. On average, one child with Down syndrome is born on every 650 newborns, which is around 0.15% (Bulic, 2013). The probability of a young couple who already have a child with Down syndrome to again get such child is small and estimated at 2.5%. The risk for other family members, including brothers and sisters, is not considered to be increased (Barisic, 2009). Down syndrome is clinically manifested in intellectual disabilities of different degrees and abnormalities in different organ systems. The main difficulty of such children is organizing information and making decisions. In addition, they fall behind in speech development, have difficulties in communication with others, and their physical and motor skills are also poorer. There are more than fifty distinctive features of Down syndrome and their number and intensity varies from child to child. The most common feature of a child with Down syndrome are: Muscular hypotonia, wide neck, inclined position of eye holes, short hands, abnormal form of ears, short and wide arms and legs, small mouth and nose with a disproportionately large tongue, short chest of unusual shape, small head (Vukovic et al., 2008; Zergollern – Cupak, Suradnici, 1998). In general, children with Down syndrome are often known as warm, kind, interesting, cheerful, good-natured, charming and of relatively good social functioning (Fidler et al., 2008; Griffith, Hastings, Nash & Hill, 2010; Rosner et al., 2004; Vukovic et al., 2008). However, like everyone else, they can be sad, careless, stubborn, defiant, quarrelsome (Cuskelly & Dadds, 1992; Vukovic et al., 2008) and express routinized, compulsive behaviors (Glenn & Cunningham, 2007). Children with Down syndrome undergo the same stages of emotional development as other children, but along the way there are certain difficulties in terms of reaching a higher level slower and staying there longer (Skrinjar, 2002). It is important to know that a child in every situation and every interpersonal relationship openly shows his emotions. Children's emotions are very strong, overwhelming the child and children are spontaneous in showing them. Children have strong authentic feelings and a limited ability to communicate them to the environment. Children with Down syndrome need extra help and support to get in touch with their own feelings, learn to recognize their feelings and talk about them, learn what kind of feelings there are, learn how to express themselves in an appropriate manner and learn to recognize emotions in others (Stub, 2010). Kasari, Greeman, and Bass (2003) suggest that, compared with other children with disabilities, children with Down syndrome pay more attention to people who are in trouble and offer more comfort in terms of pro-social response. Also, they show a much higher degree of empathy with other people than children with other disabilities. In relation to autistic children, children with Down syndrome have a greater ability of self-regulation (Bieberich & Morgan, 2004), their difficulties in the field of social cognition (such as theory of mind) are less obvious and much milder (Binnie & Williams, 2002; Yirmiya, Solomonica-Levi, Shulman & Pilowsky, 1996) and have fewer behavioral problems (Blacher & McIntyre, 2006; Ricci & Hodapp, 2003). All people are individuals and they should also be perceived as such. This also applies to people with Down syndrome. The difference between them is large, while some cannot master the basics of reading and writing, the others graduate from faculties.

2. A child with Down syndrome in family

For every parent, a birth of a child with Down syndrome is the event of extraordinary emotional charge and is accompanied by a variety of emotional reactions. "Some are becoming aware of their feelings and find exceptional power and potentials to deal with them. Some deny sadness and disappointment, frustration and anger ... Other parents are so sad and disappointed because of their child that they behave hostile and uncooperative. They retreat both physically and emotionally, reducing their interaction to a minimum. They do not mean to leave him – they love him- but can be protected only when they hold him at a distance of an arm's length. Others parents feel the impulse to run, to pretend as if their child and his disability do not exist. But that feeling is so uncomfortable that they defend themselves from it by adopting a contrary position: they begin to behave overly protective and anxious" (Greenspan, Wieder & Simons, 2003). With the arrival of a child with Down syndrome into the family, roles of all family members

are redefined and adapted to the needs of a newborn. Increased emotional, physical and financial demands often influence the functioning and well-being of the family (Dodd, Zabriskie, Widmer & Eggett, 2009). The family has a decisive role in the development of the child, and this role is even more important in the development of children with Down syndrome. Research indicates that, especially in children with intellectual disabilities, development exclusively depends on the degree to which parents offer adequate stimulation and emotional support (Pino, 2000; Venutti, de Falco, Giusti & Bornstein, 2008). Compared to families who do not have child with developmental disabilities, families with children with Down syndrome show higher levels of stress as well as greater difficulties to adapt. These families are also less involved in various social activities, care for the child is an extra financial burden, and when they observe and compare their child with children without disabilities, they see more negative features (Sanders & Morgan, 1997). However, according to the study, mothers of children with Down syndrome, compared to mothers of children with other developmental disabilities (such as autism, or mixed etiology intellectual disabilities), show less stress, greater life satisfaction (Griffith et al., 2010) and more positive parenting (Blacher, Baker & Kaladjian, 2013). Parents of children with Down syndrome, compared to parents of children with other intellectual disabilities, are less prone to depression and pessimism (Fidler et al., 2000), have a lower percentage of divorces and better function as families (Cunningham, 1996; Hodapp, Ly, Fidler & Ricci, 2001;). This phenomenon is known as the "Down syndrome advantage". Hodapp (2002, according to Stoneman, 2007) states that this "Down syndrome advantage" can result from the behavior styles of individuals with Down syndrome who, as a group, have less behavioral problems than people with other developmental disabilities, their social competences are more developed, they give positive answers to incentives of parents and other caregivers and have better developed ability to communicate. Children with Down syndrome can encourage positive parenting behaviors, such as verbal and non-verbal expression in a positive sense, warmth and love for them (e.g., hugging, kissing) (Blacher et al., 2013). Having a brother or sister with Down syndrome does not necessarily cause negative consequences. Siblings of children with Down syndrome do not differ either in the behavior, nor the competence or self-concept than the general population (Cuskelly & Gunn, 2006). To more easily overcome many difficulties that are a part of their daily routine, parents of children with developmental disabilities need help and support from their immediate and broader social community. Higher levels of parental education, higher income and better social support contribute to healthier and better functioning of family with children with Down syndrome (Hsiao, 2014). Social support can be defined as information that lead a person to believe that they are unique and loved, valued and respected and it is also important in the network of mutual obligations and communication (Cobb, 1976, according to Siklos & Kerns, 2006). Examples of social support include support of spouse, wider family and friends, opportunity to spend free time in various recreational activities as well as support from different local community programs targeted towards families with children with disabilities. Cvitkovic, Zac Ralic & Wagner Jakab (2013) found a statistically positive correlation between the degree of community's acceptance of the child's disability where the community helps families in facing problems and total life quality of families with children with Down syndrome.

For children with Down syndrome, early developmental intervention is particularly important. There are many definitions of early developmental interventions, and one of them is that the intervention is as soon as possible resolution of problems that have already occurred in children and young people (DCSF, 2010, according to Paige Smith & Rix, 2011). The goal of early intervention is to allow a child to better develop his capabilities and gain experience that he needs so that his environment is adapted in a way to encourage the whole child's development, raise his interest and attention, and encourage him to actively participate in the interaction with its environment. Early intervention and comprehensive psychological, educational and rehabilitation assistance and support to parents are crucial. With the support and information parents feel safer and more competent in raising their child with Down syndrome and to meet his special needs in a family environment (Vukovic et al., 2008).

3. A child with Down syndrome in an educational institution (kindergarten and school)

3.1 Kindergarten

For the development of a child with Down syndrome, years spent in a kindergarten have a very important role. A child with Down syndrome can learn infinitely in a kindergarten. As with all children from three to six years, developmental stages in children with Down syndrome are very different. Children in kindergarten acquire certain knowledge in the field of social experiences, mild discipline, increase of independence, coordination of coarse and fine motor skills, spending time and communicating with different people in different ways. The most important advantage of a child's stay in the kindergarten is contact with children who are at a higher level of speech development. In addition, kindergarten helps with coming to a higher level of "normalization" through contact with children of the same age who do not have a developmental disability (Ivankovic, 2003).

Any child, including a child with Down syndrome, best develops while playing. Children reveal themselves while playing and show their repressed feelings. A child with disabilities is less creative and this is where educators have a very important role. An educator can conduct well-designed introducing games, games for a better group connection, games for social learning through various projects, games for stimulating imagination, creativity and creative games (Posokhova, 1999).

Children with disabilities are a major challenge to educators. While in the past teachers felt insecure in working with such children (Kostelnik, Onaga, Rohde, & Whiren, 2004), today the situation has changed significantly. JurCevic LozanCic and Kudek Mirosevic (2014) conducted a research on the attitudes of teachers and professionals on the implementation of inclusion into regular preschools and primary schools in Croatia. According to their research, educators show motivation and a high level of sensitization to working with children with developmental disabilities. They perceive their work as quality by selecting appropriate methods of working with children with disabilities. Educators, more than teachers, support the inclusion of children with disabilities into regular elementary school system. For successful work with children with disabilities, it is important that educators have emotional balance, the ability to successfully establish contact with children and love for the children.

3.2 School

In most countries, children with Down syndrome acquire knowledge and develop their skills with their peers in regular school systems. Successful integration of these children into regular classes depends on peer acceptance and promotion of positive interaction (Lewis, 1995). The teacher plays the most important role in the integration of children with Down syndrome into the class. He/she has the task of preparing students in the class to accept a child with Down syndrome into a classroom community. Appropriate conversations make students accept the fact that there are students who are different from them. Timely notifications can direct students to accepting students with disabilities, but the actual value is achieved through them living and working together (Mustac & Vicic, 1996). There is a number of positive outcomes from the integration of children with Down syndrome: All children learn about tolerance, understanding for individual differences and respect for diversity. By encouraging social interaction in the classroom, all children learn how to communicate, use specific social skills in everyday activities, control their own behavior and to offer support to their peers (Zic Ralic & Ljubas, 2013). Integration into regular classes allows children with disabilities to develop their independence and staying and exposure to a communication rich environment contributes to their cognitive development.

4. The objective of the case studies

In order to obtain a better, more detailed and deeper insight into aspects of functioning of a person with Down syndrome in the institutional context of educational institutions we conducted two observational case studies by participating observation and in-depth interviews (Halmi, 2005). With this paper we will present descriptions of a girl in pre-school and a boy in primary school. We wanted to expand and upgrade the knowledge of how children with Down syndrome function in the educational context of achieving "*complex dynamic interactions taking place in a unique way*" in a kindergarten group and class (Cohen, Manion & Morrison, 2007).

4.1 Case Study – Ivana

At the beginning of the school year, girl Ivana, aged seven, arrived in a kindergarten group (average age 5-7 years). Before her arrival to the group, kindergarten employees conducted an individual interview with the girl's parents to find out information that is important for her stay. The teachers organized a parents' meeting to acquaint the parents of other children with the characteristics of children with Down syndrome and announce the inclusion of the girl with Down syndrome into the nursery. The educators reported about their concerns about the parents' reactions, and also the satisfaction with their positive response. What followed next was working with children, where educators rose their perception of diversity- we have different hair color, eye color, some know more letters and numbers, while some are more skilled in physical activities.

Upon her arrival, Ivana had developed cultural and hygienic habits, but her speech was not developed and she communicated with her parents non-verbally. The first two weeks Ivana spent two hours in her group, accompanied by her mother, and afterwards she would stay without her mother being there. On the first day, she walked into the group full of love and hugs around her, she knew how to feel when someone was sad or in bad mood, she would solve all problems with tenderness and hugs. Communication between Ivana and other children was non-verbal; she followed their instructions and understood basic terms. The girl often stayed in other kindergarten groups, she especially liked playing with other children during their stay in the yard and terrace. Children could learn a lot from Ivana, especially how to accept a person who is very different from them, how to help her and make her feel good in a group, helping her in participating in their daily routines (serving table for breakfast, washing hands, drawing, playing with Legos). There were days when Ivana would come to the group sad, and sometimes angry. On those days, she did not want to participate in activities with other children, but she liked dancing and listening to music. Children noticed her behavior and did not want to disturb her, they just played the songs she loved listening. This is how they learned being tolerant and flexible to others in their surrounding. Sometimes, when walking through the city, Ivana could not walk or follow the pace of the group, which resulted in returning to the kindergarten earlier. Children worried if she could walk and if she needs any help and they were not angry when the walk ended sooner. Sometimes other children did not want to talk because they wanted to be like Ivana. Cooperation with Ivana's parents was excellent; they accepted educators' suggestions who respected them as equal partners in raising their daughter. Each month they had individual conversations where they shared experiences about what is going on in the kindergarten and at home.

4.2 Case Study – Peter

Peter started school at age of 8, one year later than usual. Before school, he attended kindergarten, since he was two and a half years old. He was the fifth child in the family, brothers and sisters being older than him. Upon starting school, he spoke only a few words, monosyllable or two-syllable (e.g. mom, dad, lion). He knew the capital letters: A, E, I, O, U, M, N. Peter is now a fourth-grade student. He has developed hygienic habits; he dresses independently, but slower than other children. He participates in a tailored program with an individualized approach. He makes sentences of few words, but depending on the voices in them, pronounces them more or less unintelligibly and incorrectly. He reads printed letters, transcribes words in capital letters, but cannot write from dictation; because the ability for voice analysis has not been adopted (he possibly writes two letters).

At school, from the first grade, he has a personal assistant who helps him in work. In addition, parents organized private lessons with speech therapist (3 times a week) and English lessons (2 times a week) so that Peter could master the courses at school more easily. Over the weekend, a professional is hired to go over the school content and practice new skills with him (e.g. he is currently practicing writing cursive letters). His mom points out that after school hours Peter studies and practices about three hours a days and he has gotten used to it because he started with functional learning very early, since he was 2,5. He goes to therapeutical horseback riding, is an active scout, is involved in religious group activities, practices judo twice a week, goes swimming once a week. As a very important determinant in working with Peter, his mother mentions principles and perseverance. The whole family is working with Peter, especially mother who is unemployed and is fully dedicated to providing help and support to Peter's growing up, learning and developing.

His teacher makes him a lot of didactically- designed and appropriate materials (papers with a lot of pictures and photographs, short texts written in larger font, connecting tasks etc.) (Figure 1)

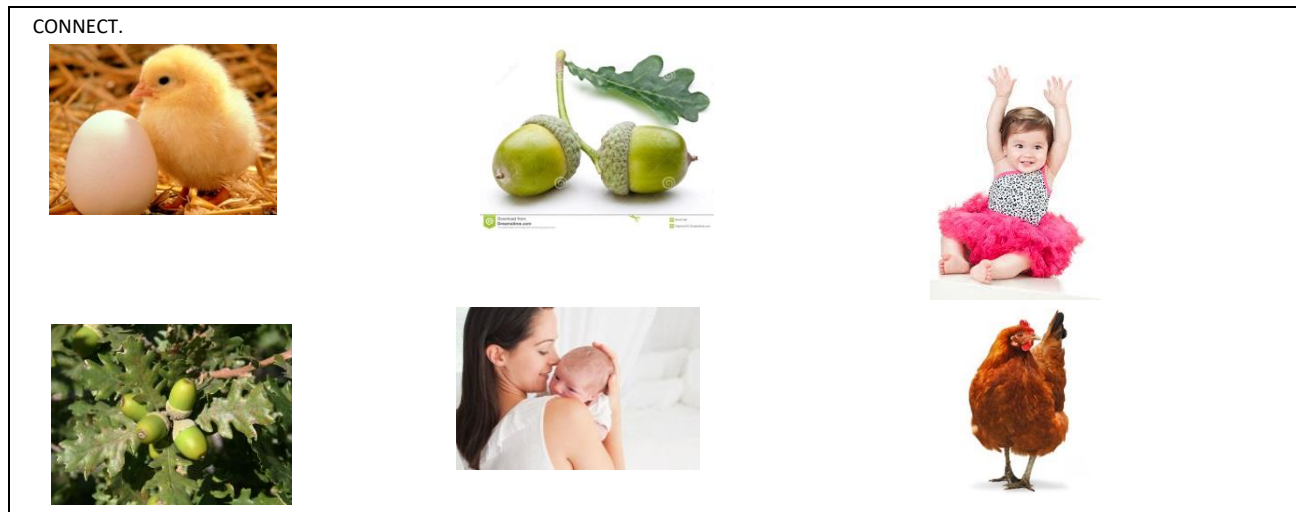


Figure 1. Lecture slip

He can count to 10 by touching his fingers, always starting from 1. In the mathematics lessons he always uses didactic material Numicon by which he adds and subtracts even three-digit numbers (Figure 2). He multiplies and divides by using the image multiplication tables. He is happy when he calculates something, lifting his thumb and triumphantly exclaiming: "Yes!".



Figure 2. The didactic material Numicon

He very carefully listens to guidelines and works in accordance with the instructions, what his teachers attributes to his aptness, being a result of the exceptional commitment of all family members who work with Peter a lot. During the class, he tells his teacher she is pretty and that he loves her. His mom says that the teacher is a great role model and authority for Peter. Relentless in work, he often requires additional tasks. He participates in all the activities of class, goes on all field trips and participates in events (Figure 3). The teacher notices sudden positive changes in Peter's adoption of content and periods of "sleep" mode. He responds very positively to praise which is extremely motivating for him.



Figure 3. Peter at the zoo

Peter can name all children in his class. He says he likes going to school, the teacher says he is not absent often, and when he is absent, it is because he is ill or sad. He sometimes comes to school on his own, and sometimes accompanied by his parents or family members (he walks the sidewalk and crosses streets correctly). He is favorite in his class because he is amiable to all students (he invited them all to his birthday). He has a developed sense of humor. He often laughs and suggests a "mischief" look. The students accepted Peter as an equal member of their collective, respecting his specificity. Every year, on March 21st, World Day of People with Down syndrome, students wear colorful socks in support to not only Peter, but all people with Down syndrome.



Figure 4. Peter in class on the World Day of People with Down Syndrome

5. Conclusion

In this paper we presented two case studies, a girl Ivana in kindergarten and a boy Peter in elementary school. Ivana's arrival to the nursery is a beginning of a challenging adventure not only for her and her family, but also for other children and kindergarten staff. Positive developments are observed by both Ivana's parents and kindergarten employees.

Peter comes to school with a smile, and more importantly, leaves the school with a smile. It should be noted once more that the engagement of Peter family is not usual. Exceptional energy, time, perseverance and faith are invested in Peter's growing up. This is supported by the fact that they see Peter as a gift that enriched their lives.

A child with Down syndrome, like any other child, has his own potential and capabilities, and it is a task of adults to help him develop them in order to successfully integrate into society. Children with Down syndrome, as well as other children with disabilities, are the most vulnerable part of the population and society and to grow up and develop, they need love, affection, care and concern of the whole society. Unfortunately, we still often perceive their appearance and damage, but not their personality. The most important thing we can do is remember that the illness of a child is only a small part of his personality and existence, no matter how serious it is and how significant impact it might have (Juul, 2004).

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