

# ANALYSIS OF EDUCATION SPECIFICATIONS FOR CHILDREN WITH DOWN SYNDROME AT EARLY AGE

Jana Balazova

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## Abstract

The study further analyzes the specifics of early childhood education with Down syndrome, which are directly related to genetics, health and factors affecting early childhood education, but also stimulation at home, family cooperation with professionals, personal growth of individual family members, influenced by their life experiences and their social environment.

## Key words

specifics of education, a child with Down syndrome, early age

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## Introduction

The child with Down syndrome (hereafter referred to as DS), even in the era of inclusion trend, is **still a big scare** for prospective/existing parents and grandparents, and also for doctors, special educators, psychologists and consequently for teachers, educators, etc., which may be related to the fact that DS is one of the common causes of intellectual and developmental delays. Our descriptive research problem concerns the specifics of early childhood education of a child with DS related to particular areas, intending to contribute to a better implementation of inclusive education from the child's early age.

## Children with Down syndrome and the educational environment

Children with DS have a different genetic makeup - they have an extra chromosome in the 21st pair, which affects many developmental processes. However, it is necessary to note the words of Damborska (1984), who expressed that **it is not the genetic code that is decisive** but motivation. The environment in which a child grows up can significantly influence his/her development through interactions of different nature – with people, inanimate objects or even symbols (Vagnerova, 2008). Badurikova (2010/2011) states that education helps to develop personality when children realize that they are the subject of education (active participants). Spontaneous education is the most intensive and effective. Montessori (In Krusinska, 2009) emphasized the preparation of the educational environment and believed that the child's personality grows through intense inner work in contact with a stimulating environment. It is a free environment that respects the child's current developmental stage or is a step ahead. In such an environment, the child's psyche has the space to develop naturally and manifest its hidden secrets (Montessori, 2012). Regarding a family with a child with DS, it should be remembered, as Turzak and Kurincova (2016) write, that the family environment is contoured by the child's diagnosis and health status,

also the family structure, the individual roles of the family members are modified by the responsibility in caring for the child and its scope.

Some developmental changes result from the child's specific discoveries, but many arise from social stimulation (Vygotsky, 1970). The child with DS needs to be guided along life's journey so that he or she is gradually encouraged in independence and responsibility and has room for the gradual internalization of cultural symbols and traits (Vygotsky, 1970). Mediation is ideal and can be considered the fundamental cause of successful inclusive education. The views of neuroscientists and neuropsychologists are also favorable. Believing that the brain can change its structure and function through thought and activity brings great hope to many parents of children with DS. It is not advisable to expect miracles and to point to pseudo-curvature (this is also happening nowadays), but it is more appropriate to look for viable ways following the current possibilities, abilities of children with DS, their families, but also schools (in which they are interested) so that children with DS can gradually (despite the adversity) become independent and productive people.

Children with DS need help to discover something important for themselves in a way that includes thoughts and feelings. The accompanying person should be one step ahead of the child, i. e. the child, with appropriate help, can achieve more than we would expect given his/her current developmental level. According to Vygotsky (1970), this is the so-called **zone of proximal development** – one step ahead of the child's current state of development. Vancova (2013) points out two reasons why it is important to ensure the supply of stimuli, and thus afferent processes, in all available alternative or complementary ways. One is the need to saturate the central nervous system with the necessary quantity and quality of stimuli in the right sequence, which is essential for preventing developmental limitations at multiple levels (motor, sensory, cognitive, communicative and social). The second reason is the need to prevent the emergence of, e. g. motor limitations - 'learned disuse'. She adds that, from a psychological perspective, psychomotorics is a system that triggers sensorimotor processes that provide sensory correction of movements and thus form the basis for practical thinking.

The gradual steps are related to the realization, as stated by Vancova (2013), Vingralkova (2016, 2018), and Greil (2019), that psychomotor development is a complex ontogenetic process of gradual transition from lower levels of regulation from phylogenetically older structures of the central nervous system to younger structures. Vancova (2013) adds that the emergence of any physical activity is carried out based on conditioned-reflex activity on the principle of hierarchy and heterochrony of the development of each function. The education of a child with DS brings different specifics, and the principles applied in the process of education can be a help. At the same time, it is worth remembering that not only the parents and the family environment influence the child with DS, but also the child in question reciprocally influences his/her immediate family environment in different ways.

## Methodology

The aim of the research was to describe the specifics of the early education of a child with DS and to characterize the principles of the parents' approach to the education of a child with DS that contribute to the development of resilience in the child. We tried to fulfill this goal by answering **the primary research question** – *What are the specifics of the early education of a child with DS?* – and secondary research questions: What are the specifics of education of a child with DS related to? How have the specifics of the education of a child with DS affected the life of the family? What principles of education for a child with DS contribute to building resilience in a given child?

The focus of our research was a detailed and in-depth examination of one case through a case study. Not as a data collection technique ("data collection method") but as a research method ("research method"). Chrastina (2019, p. 99) states, "The descriptive case study attempts to capture a full, dense description of the case," it is a detailed analysis of the individuality of the case that, together with the context of the case being studied, creates the conditions for knowing the case through an intensive discovery, a study, i.e., a process of exploration (Becker, 1970, In Chrastina, 2019). According to Hendl (2016), a descriptive case study is meant to deliver a comprehensive description or to describe relationships in their entirety.

The main research method was a **descriptive holistic single-case study**, through which we tried to approach the specificities of the education of a child with DS to provide not only basic information about the child with DS and his/her family but also a systematic description of the actions taken, reactions, responses and effects, which we compared with professional perspectives.

We conducted the research in **five stages**:

Stage 1: Finding a willing family with a child with DS, first contacts, interviews focusing on medical history and observation of the family's environment and family life.

Stage 2: Conduct semi-structured and unstructured interviews.

Stage 3: Study of medical reports and reports from other professionals, as well as the study of materials provided by the family about their child with DS and the whole family.

Stage 4: Analysis and synthesis of the collected information and data to summarise the specifics of the early education of the child with DS from the perspective of the persons involved.

Stage 5: Interpretation of the obtained data in relation to the theoretical part of the study, the research's defined aim, and the research questions.

The necessary **information and data were obtained** through the history of the child with DS, family history, interviews with the parents of the child with DS, studying reports from professionals (doctors, a special, therapeutic educator, a psychologist, and a speech therapist), unstructured interviews – with the consent of the parents - with the professionals mentioned above, educators in the kindergarten, observation in the home environment and studying the documentation of the child with DS (written materials: mother's

records, completed tests recommended by experts, summarised recommendations of experts, visual materials: photographs, drawings, video recordings, etc.).

We interviewed both parents at the same time (5 meetings) in their home environment without the presence of the children, and we interviewed the mother (5 sessions) also without the presence of the children. We made audio recordings and took notes during the interviews with the parent's consent. The audiotapes were subsequently transcribed and analyzed. We approached professionals who work with a child with DS only after parental consent and a study of the reports from the professionals (provided for review by the parents of the child with DS). We conducted the interviews in their workplace.

We implemented the observation in the home environment on the day of the interview with the parents (before going to their grandparents or after the children's return from grandparents). During the observation, we took notes, which we then analyzed.

Our intention was not only to provide a detailed description of the case under study (cf. Gavora, 2007) but, following the recommendations by Hendl (2005), to bring descriptions and relations towards the context of the data collection procedure. The analysis process proceeded sequentially, adhering to the focus-case-oriented analysis, "case-oriented analysis", in which the central concept is the case in its holistic identity (cf. Chrastina, 2019).

First, we prepared and planned data organization so that we could gradually search for the key, central categories ("core categories") and define the emerging concept ("emergent concepts") through coding (context codes, activity codes, event codes, and strategy codes). The process continued with note-taking, observations and initial attempts to interpret (assign meaning to what was found) what was discovered through the categories capturing the essence. The above was elaborated in the form of **qualitative research with a circular process**, capturing the life of a child with DS and his/her family in an authentic setting to answer the research questions. According to Seda (2007), the circular process is manifested by overlapping the different phases, i. e., data collection, analysis and interpretation are carried out in parallel, while there is the possibility of returning to the previous phase and modifying it.

## Results

Our research involved a complete family of four: a father (45 years old), a mother (39 years old), an older child with DS (10 years old), and a younger child (7 years old). Both parents are employed, and the children, despite the age difference, attend together the 2nd grade of a primary school in a nearby town (there is no school in the village). The child with DS was healthy until age three and made reasonable progress in growth and development. The exception was stagnation at the age of 4 – 5 years when digestive and rheumatological problems manifested themselves, and the child underwent treatment with methotrexate, which he tolerated poorly. Rheumatology, ophthalmology, and gastroenterology were added to regular examinations. In addition to the doctors, the parents worked with specialists in the field of

motor development, special education intervention, speech therapy, and early intervention from the early age of the child with DS. We dare to say that the measures taken so far by the parents have benefited not only the older child with DS but also the younger child and the parents themselves. The parents sought and incorporated the recommendations into their daily routine, which implies that they used, used the usual routines, activities, and games for stimulation. Although they reduced or even changed their social contacts (which is natural after the birth of children), they did not close or try to coerce in the sense of the right to education in kindergarten.

***The specificities of educating a child with Down's syndrome***

In the case of children with DS, from the aspect of the family environment, it is not only a matter of upbringing. Parents try to stimulate the child on the basis of the recommendations of experts (doctors, early intervention advisers, etc.), i. e. they not only provide upbringing but also try to educate in a particular sense.

At the same time, children with DS are rarely admitted to a kindergarten for children without special educational needs (from the age of 3 years in the form of school integration). For this reason, we use the term education already in the context of the child's early age and the family environment in combination with the kindergarten environment.

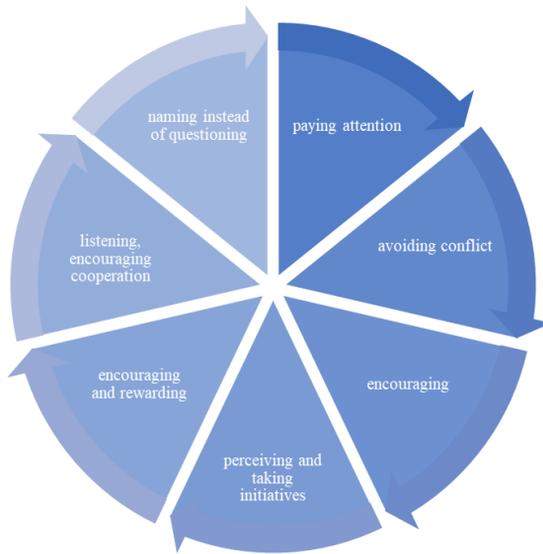
**Table 1** Specificities of the early education of a child with DS from the parent's point of view (own elaboration)

Specificity	Context	Measures
FEAR	<ul style="list-style-type: none"> <li>. texts about children with DS are a scarecrow</li> <li>. doctors lend a helping hand, but also fear related to prognoses</li> </ul>	<ul style="list-style-type: none"> <li>. perception of the real child</li> <li>. perception of real feelings from real life</li> <li>. finding the courage to have a peer conversation with doctors</li> </ul>
PREVENTION	<ul style="list-style-type: none"> <li>. regular preventive examinations are needed</li> <li>. regular meetings, interventions, and exercises with specialists are desirable</li> </ul>	<ul style="list-style-type: none"> <li>. it is advisable to take regular breaks from seeing doctors</li> <li>. indulge in considering whether it makes sense to devote time, energy, finances</li> </ul>
STIMULATION	<ul style="list-style-type: none"> <li>. stimulation of psychomotor development is needed</li> <li>. a wide range of options</li> <li>. pressure during implementation</li> </ul>	<ul style="list-style-type: none"> <li>. looking for ways to incorporate stimulation into everyday life</li> <li>. accompanying person</li> <li>. minimising manipulation</li> </ul>
INTERVENTION	<ul style="list-style-type: none"> <li>. regular meetings with a professional not only push, and encourage but also frustrate</li> </ul>	<ul style="list-style-type: none"> <li>. discuss the child's current condition and the "next zone of development"</li> <li>. asking the professionals: what is working, what to support, what to develop further</li> <li>. to see mistakes as challenges</li> <li>. discuss feelings</li> </ul>
FEELINGS OF NON-ACCEPTANCE	<ul style="list-style-type: none"> <li>. the child with DS is still perceived as different</li> </ul>	<ul style="list-style-type: none"> <li>. emotions are a natural part of life, and it is appropriate to look for ways to learn to observe and accept them (faith, psychotherapy, music therapy, meditation, exercise, mandalas of emotions, etc.)</li> </ul>
SURPRISE	<ul style="list-style-type: none"> <li>. initial ideas are not pleasant</li> </ul>	<ul style="list-style-type: none"> <li>. life here and now brings many pleasant surprises</li> </ul>
SUFFERING or JOY	<ul style="list-style-type: none"> <li>. the child with DS is presented as a suffering child</li> <li>. a family with a child with DS is presented as a suffering family</li> </ul>	<ul style="list-style-type: none"> <li>. a perceptive, empathetic, sensitive, friendly child with DS brings many opportunities to experience joy every day - just indulge in it</li> </ul>

Based on the analysis of the collected data and information, we conclude that **the specifics of the education of a child with DS are related** not only to genetics and the child's natural activity but also to stimulation (ideally in collaboration with early intervention specialists). In Table 1, we summarise and present the seven most prominent specificities of the education of a child with DS from the parent's point of view, as well as possible measures.

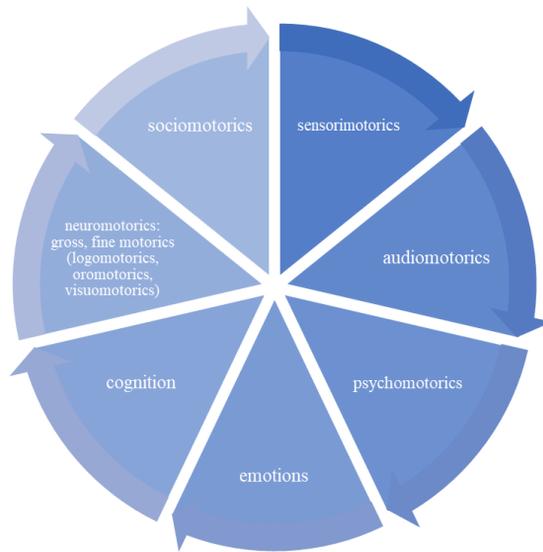
Due to hypotonia and macroglossia, speech developed more slowly, respectively. At 1.3 years of age, the child was diagnosed by a speech therapist with impaired speech development. However, the parents sought opportunities for communication because they perceived the child's interest in communication. Following the speech therapist's recommendation, they tried to focus on the development of communication skills and the speech itself through signing, in conjunction with the play, activities of daily living, appropriate exercise (especially in the home environment and in the

outpatient setting), and orofacial stimulation. Despite the poor vocabulary, the child support in communication made progress - the child with DS at 27 months of age combined words and signing not only at the level of one-word, two-word, but also multi-word sentences. However, it was not easy; based on interviews with parents and professionals, we summarized the principles: paying attention, avoiding conflict, encouraging, taking and accepting initiatives, encouraging and appreciating, listening, encouraging cooperation, naming instead of questioning instead of asking questions (Figure 1), which influenced the development of communication skills and speech development at an early age.



**Figure 1** Principles influencing the development of communication skills and speech development (own elaboration)

Parents of a child with DS have even realized that communication through signing can not only support the development of communication skills but also gross and fine motor skills (i.e., oromotor skills), thinking, the speech itself, language, i.e., motor, sensory, psychological, emotional and social areas, or areas related to the development of speech, language and communication (Figure 2) are also related to the complex development of personality in terms of functionality.

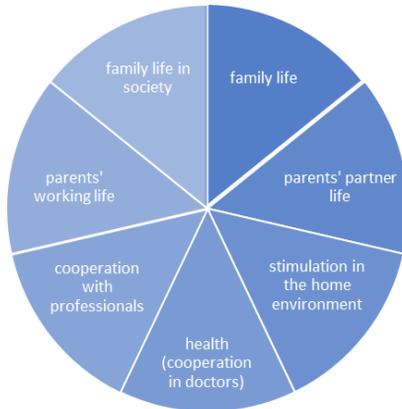


**Figure 2** Areas related to the development of speech, language and communication skills (own elaboration)

- Sensory: they focused on whole-body tactile perception, the development of other senses, not excluding kinesthetics, perception of the position of one's own body and later orientation in space.
- In the framework of audiomotorics, they developed the perception of sounds and tried to reduce sensitivity to sounds. Dad smiled: *"When I was pushing the pram, and the tractor drove by, the baby would continue to sleep, but when an aunt or a friend stopped by, he would wake up in a gentle whisper."*
- Psychomotor skills are a very broad area, but parents clearly emphasized the need for the child to be actively involved in the process. Gradually, they focused on functionality in the area of self-care (space to play, toys, aids; eating skills; undressing and later dressing; toilet use from the first months during breastfeeding; hygiene habits).
- Emotions: this was a challenge for the whole family - to become aware of, observe and accept their emotions. To indulge in anger, fear, and sadness and to indulge in them with the children as well.
- Cognition: an area that was markedly highlighted by doctors, by some experts, as problematic. In my father's words, *"We were and are fortunate to have had and can have bright moments and build on them."*
- Neuromotorics: according to the medical reports, the child with DS is under follow-up, and the doctor is positive about the motivation of the child with DS.
- Sociomotorics: we attach the father's comment, *"On the one hand, a tough nut to crack, but on the other hand, great admiration for the way he makes contacts."* The familiar environment of the extended family, playgrounds, kindergarten, and primary school is just a big help.

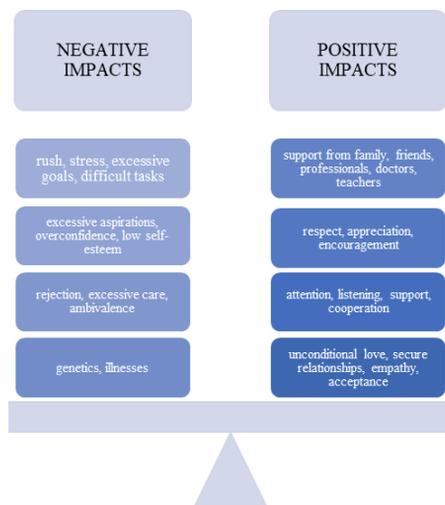
They often looked for opportunities for smaller steps so that both the child with DS and the parent had the opportunity to experience understanding and success (zipping up the zipper was stepped out: first just looking for the zipper, then looking for the moving parts on it, then trying to connect the moving parts, waiting patiently for the parts to be connected and finishing the rest for the child, and only at the last stage expecting the zipper to be zipped up). They noticed and showed natural joy in the small signs of progress of both children, which were about the process and not the outcome (noticing the child's efforts to take off the shoe), teaching the children to observe with humility and acceptance, and the children learning this from them. They tried to be one step ahead of the child (developmental charts can be a great help if frustration with that age is not imminent or can be avoided by tapping over that line or making their own chart). They asked questions: Is what I'm doing working? How can I stimulate the child's interest in the activity? How can daily routines provide opportunities to practice goals?

The above areas of stimulation also influence family life and vice versa in the following areas: family life, parents' partner life, stimulation in the home environment, health - cooperation with doctors, cooperation with other professionals, parents' working life, family life in the community (Figure 3).



**Figure 3** Areas related to the family life of a child with DS (own elaboration)

Parents tried to stimulate the above areas from an early age and accompany the child with DS to increase his functionality and resilience (Figure 4) so that he would be independent, confident, and able to live in society.



**Figure 4** Resilience of the child with DS (own elaboration)

### ***Principles of education for a child with Down syndrome***

The principles of educating a child with DS that contribute to building resilience in the child (Figure 4) are directly related to respect, dignity, unconditional love, empathy, acceptance, valuing, building trust, encouraging, listening, guiding, accepting the child's initiatives, as well as supporting family, friends, colleagues, collaborating with health professionals, educating, stimulating, as well as looking for potential, improvising, modifying, and finding new paths. E. g. communication using the sign language of the child with DS, which reassured the parents of the child with DS about the possibility of communicating. Consequently, communication respecting the possibilities and abilities to produce words not only enabled vocabulary development and communication skills but also aided the development of motor skills and cognition - communication by using a combination of signing and words enabled the production of multi-word sentences (cf. Mason-Apps, Buckley, 2018 and 2020).

1. Clarification of family and individual family members' values: the arrival of a child with DS required a reassessment of the value system, i.e., own priorities, family priorities and an assertive approach to self, each other and the wider family. However, parents admit that they are not always clear about their priorities, especially concerning work life, as circumstances often push them back. Parents are forced to either resign or try to assertively manage the situation, which is difficult (Figure 3).
2. Feelings of security, safety and trust: parents need to be aware of what makes them feel secure and safe and when and to whom they trust. In this context, they had the opportunity to indulge - to become aware of, observe, and process - the new situation that had arisen with the birth of a child with DS. At the same time, through this awareness of their process of acceptance of their child with DS they tried. They are trying to afford time and opportunities for their child with DS to be accepted by the wider family, people from the community, peers, staff at the nursery,

primary and art school. Mother's statement: "They too need space and time to rebuild a sense of security, safety and trust in us as a family and our child with DS. Nothing truly positive in a relationship comes by order or force, by asserting the right".

3. Environmental readiness: since a child at a young age learns most in the ordinary home environment; parents try to use the activities of ordinary life to stimulate, motivate, and space to communicate, i.e. if we have intention, purpose, meaning and desire to engage in an activity, a solution, it is ideal, and we can look for connections, linkages.
4. Sense of competence: in the same way that parents need to feel competent enough to educate their child with stimulation and responsible enough (not just ready) to perform tasks. Children with DS need to feel competent to do something in particular; it is desirable if the child with DS is indulged and allowed to feel that he or she can do it. We need to convey the task to the child, so they can solve it.
5. Space and time to work on their own: there is a difference between following instructions and being actively involved - feeling important about the process of working on their own is extremely important, as is working with the mistake (not worrying but rising to the challenge). Ideally, the child should be able to enjoy their own work.
6. Exactitude: rituals, rules, and clear instructions are an important part of everyday family life, and thanks to them, we perceive boundaries and can indulge in freedom.
7. Joy, fun, and enthusiasm for active participation: a positive attitude brings strength and energy, and humor brings relaxation and reassurance.
8. Empathy, encouragement, praise and constructive criticism: we learn throughout our lives, and often children are our teachers.
9. Communication: sharing ideas and information is enriching.
10. Respect: being respected and respectful (e. g., a child shows enough - they no longer want to eat/drink/play/sleep - and we respect that).
11. A reasonable degree of tolerance and partial benevolence: are part of being a person who realizes that he/she is not perfect and does not require perfection.
12. Togetherness: the feeling of belonging somewhere is fundamental to one's perception of oneself concerning others.
13. Strategy preparation: the realization that we are not acting randomly but that we are moving towards a goal is related not only to set goals but also to finding how to achieve them, preparing for change, coping with increasing demands, etc.
14. Modification: in the sense of creativity, but also of learning, surviving, and gradually building resilience.
15. Patience: refers to the whole breadth and depth of the process of education and stimulation.

We conclude the summary of the principles with the mother's statement, "*For me, the most important thing (not only related to living with a child with Down syndrome) or what I perceive as the mainstays are - to have or find the desire to live together, to grow, to learn to be in the present and to look for*

*what we have reason to be thankful for."* And a father who emphasized, *"The most important thing is to accept each other and love each other."*

The above principles are relevant to the case we addressed in our research. These are not principles that we can generalize. However, they can inspire parents or serve as a basis for further activities and research that could be based on the realization that:

- Parents of children with DS need a partner's helping hand to become aware of their fears and discover the desire to observe the child and accept him/her. They need to be informed about why preventive examinations are important and, simultaneously, to be told the results in a clear, concise, and understandable way.
- Parents do not need tasks to listen to lectures on psychomotor development. They need guidance and advice to be able to stimulate their child from an early age to support them in the home environment. And ideally, through experience, they will very easily understand the difference between manipulation and stimulation.
- Parents want to help the child and not hurt him. Therefore, they should know that a child is born into a cultural society that subsequently influences its development throughout life (Vygotsky, 1970). For children with DS, it is not only the diagnosis itself, currently perceived as a social abnormality, that causes difficulties, but also the perception of the child as a punishment child who is a burden for the family, or, on the contrary, the family's excessive efforts to protect the child, to give him or her extra attention.
- Parents do not even need a lecture on speech development. They need help to be able to gradually, in small steps, incorporate advice, guidelines, exercises, and games into everyday life or to implement therapy for impaired communication skills because, as Lechta (2002) writes, the most ideal is a holistic - holistic approach to therapy, which is best applied in the home environment.
- Parents do not need to read or hear learned prognoses regarding children with DS in connection with their low mental level. We should now bear in mind that the uniqueness of people with DS and their achievements show that the brain, muscles and metabolism are not fixed at birth, but the interaction between the innate and the acquired plays a large role (London, 2010).

## **Conclusions**

A child with DS is born with a risk, i.e., multiple symptoms that, if manifested, will affect or limit the child's development in many areas. In addition to sensory, psychomotor and psychomotor stimulation, the parents of the child with DS tried to guide in the areas of emotional, cognitive and speech development, especially in a natural environment that was close to them and where they felt comfortable (house, garden, nearby woods), and in cooperation with professionals. They tried to observe the children more, compare less and look for opportunities to stimulate rather than manipulate.

In our research, we focused on one family - according to Chrastin (2019), this is a "family case study" – so we cannot generalize the data and research findings. However, we have tried to contribute to the awareness that the world is a complex dynamic complex that requires exploration in context and acceptance of different perspectives, which is in line with a transdisciplinary approach and the effective implementation of inclusive education.

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PaedDr. Jana Balážová, PhD.  
Constantine the Philosopher University in Nitra  
Faculty of Education  
Department of Education  
Dražovská cesta 4, 949 01 Nitra  
Slovakia  
jbalazova@ukf.sk