Trizomie 21

We Love Being Here

The beauty of life with people who have Trisomy 21 (Down Syndrome)



Publication
NOT JUST FOR PARENTS

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Kubík

My name is Kubík and I love being alive.

I'm 5. I love riding on my balance bike, drawing, running down hills, feeding the fish in the aquarium, looking at books and pictures, watching cartoons, and I love it when Mommy or Daddy read me stories.

I'm happy with my family. I play with my older sister a lot and thanks to her I like playing with dolls and playing house.

My parents knew I had Down syndrome back when I was just the size of a bean and I still lived in Mommy's tummy. I was worried what would happen to me when the ultrasound showed that I had an unusually thick neck, small nasal bone, and short arm and leg bones. The doctors mainly saw problems and imperfections in me. I was scared. But Mommy, Daddy, my sister and our whole family accepted me the way I am, and they love me.

I learn slowly, but I am learning. I've been out of diapers for almost a year and a half now. I can feed myself and I can say "Daddy", "Mommy", my name Kuba, "cat", "flower", "no, no, no"... and "me".

I like counting to 10 and I love bathtime. I love sledding and playing in the snow and playing pretend with my favorite stuffed animals. I enjoy music and dancing and most of all going on the swings. Mommy and Daddy are teaching me my ABCs and they're helping me (and my sister helps too) not to be afraid of new challenges.

In return, I teach my family to give more hugs and to live each moment to the absolute fullest. We all make each other's lives more complete. When I look around me, I don't actually see anyone who's perfect or has no problems at all. So, I don't think it really matters much that I have this one little extra chromosome, do you?

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Trizomie21

Introduction

Dear parents and other readers,
You are reading a publication about children with Trisomy 21 (Down syndrome) that bears the mark of personal experience from many of the parents, siblings, and experts who care for and work with children with Down syndrome. Their testimony confirms that despite all its challenges, life with our children is beautiful, gratifying, and enriching.

These extraordinary children need extra care and patience in their lives, but they also become our teachers as they remind us of our often neglected humanity. They have the gift of seeing the world as it should be. They defend their own existence not with physical strength or performance, but with brilliant smiles that come straight from the heart. They give us a rare opportunity to show them the unconditional love that their parents are particularly inclined to through their own human nature. The rewards are many-fold: gratitude, a unique sense of humor, and a fascinating joy in existence itself and the little things in life.

1.

The first part of this publication features authorized excerpts from interviews with Dr. Jaroslav Šturma, a clinical psychologist who has spent years studying the psychological development and integration of children with disabilities. He studied under and later worked with the renowned child psychologist Professor Zdeněk Matějček. He founded and spent many years as head of the Paprsek Children's Center, and he also teaches at the Faculty of Philosophy at Charles University. He is a member of the Czech-Moravian Psychological Society and Pontifical Academy for Life. Apart from his work with children in his professional life, he and his wife have five children and also acted as foster parents to a disabled little boy.

2.

The second part of the publication presents an overview of the therapies suitable for children with Down syndrome from birth onwards that can give them a positive start on life and have on impact on their development. Early intervention is irreplaceable and also helps deepen our relationship with our child. Regular cooperation between parent, child and therapist will bear fruit and help each child reach their full potential. Always keep in mind, of course, that each child is unique and has different needs, gifts, and abilities. Avoid the temptation to compare your child with others, but instead let them learn and develop at their own pace and take joy in each step they make in the right direction.

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– Publication not just for parents –

Part 1

What meaning do people with Down syndrome have in our society?

Talking with Jaroslav Šturma, clinical psychologist



People with disabilities, including Down syndrome, offer opportunities for their loved ones, their siblings, and everyone else around them, including those of us who work with them. They encourage us to grow our humanity and empathy with other people.

Children with Down syndrome do not experience subjective suffering. They belong in our society and they have a great impact upon it. We need to minimize the disadvantages they face where possible, but we also have to keep in mind that disease and disability are a natural part of human life. They help make this world even more human. It is also important that we learn to truly see and accept them. That is why these children and their families deserve recognition and support.

The presence and existence of these children also has an impact on scientific knowledge. For instance, Professor J. Lejeune's discovery of the cause of Down syndrome, that being trisomy of the 21st chromosome, contributed to the study of genetics, the development of examination techniques, and options to help even before the baby is born.

I want to say, and this is my private confession, that children with Down syndrome are probably closest to my own heart. **They usually have hearts of gold. Despite the problems** they may have with their health, such as heart operations, **life with these children is enriching and rewarding. They are able to return the love they receive. And sometimes that is more important than a high IQ. The world today is not lacking in intelligent people, but it does not have nearly enough people whose hearts are in the right place. Children with Down syndrome have just that, and in that sense they give the world something it hardly ever gets. Therapy.**

Life is a gift

"From a scientific standpoint, the question of when a new human life begins is indisputable. Human life begins at conception in the form of a single cell. Conception signifies a transformation from cells produced by the father and mother into a cell that possesses a complete human genome and constitutes a new human being. An unborn life in the womb is without doubt a human being.

An unborn life in the womb is a human. The evidence for this is undeniable. Since the parents are human beings—members of the species Homo sapiens (wise man) — and the embryo is programmed to grow exactly like them, it, too, is a new human being—a human. This new life is obviously very young and small, but it is no less human than we are. From a scientific and medical standpoint, these facts are beyond doubt true."

Dr. Jacques de Vos



Zuzana

About Zuzana

First and foremost, Zuzana is a great girl. I often think that today's world doesn't deserve her. The moments where her honest, straightforward thinking and simple kindness shine through break my heart. I always find myself thinking that she is better than we are. It worries me: on the one hand, I can see that she has qualities people today desperately need, but on the other hand I sometimes worry because I don't trust that the world will have enough understanding, consideration and will to support and protect people like her. At times like that, there's nothing I can do but stand before God and bask in His power, be filled with optimism and take joy once more in the beautiful creation that is my daughter Zuzana, who was born with Down syndrome.

I remember (and still experience today) many displays of God's love and assurances that He is with us, but I'd like to share one of the first in particular. One morning when Zuzana was still a baby, she was asleep in her crib and I wasn't thinking about anything, just existing. I looked at the wall and saw in my imagination a massive pile of gemstones. They were all shining together, colors brilliant, shining bright, full of light and life, like they were all just chattering away together. Next to the pile, just a short distance away, lay a single gemstone with a piercing white light, so pure and shining so far! And so perfect. It was like God was saying that the gemstone was Zuzana: "You see? **She's a gemstone too**. She's just as precious as the other gemstones. And look at that light! Can anybody say that blue light is better than red, that green is better than orange, or that yellow is better than purple? **And is a white gemstone worse than a colorful one?**" That was when I saw who my daughter with Down syndrome really is from the inside.

Today Zuzana is 23 years old... She had amazing friends from preschool all the way through middle school and spent time with them outside of school as well. I say it all the time, but I'll say it again: Zuzana's friends and the time she spent with them had the biggest impact on her. Whether it was summer trips with my friends' families and children, birthday parties, holidays – there was so much! The other moms and I were always organizing something. Zuzana's visits at her friends' houses (or theirs at our place) often stretched into sleepovers of two or three days. As the children got older, the other moms and I didn't have to intervene in their games

About Zuzana

as often to motivate them, because as the girls got older, their games got more imaginative. They put on plays, ran beauty parlors, did fashion shows, made videos... Later they acted together in real plays and performed together at concerts... They really loved each other. They spent a lot of time together all through preschool and middle school. That childhood bond remained with them even afterwards. Her friends all went to different schools, but so far they still see each other at least for a few days, and with the exception of this year when we can't visit each other because of COVID, not a single birthday has passed that they didn't come to wish Zuzana well, and even now during lockdown they still call her online.

I am convinced that their whole friendship was able to develop because it never occurred to our family to isolate Zuzana or treat her differently. She also had a sister who was five years older and spent time with her, which also helped Zuzana to develop naturally.



When the kids were little, I loved learning, exploring, and discovering the world with them... That's just how I am. I don't remember ever struggling with the time I spent with Johana or Zuzana. And so we taught Zuzana everything we could think of, and she repaid us with enthusiastic effort.

It was Naďa Kafková, however, who brought order into our spontaneous educational process. We spent an unexpected two weeks together in České Budějovice and she put me onto a new teaching method. The systematic approach paid off and Zuzana worked hard. Her personality meant that



we could work with her on learning, just like it showed up in her relationships with her first friends in preschool. She was never sidelined, always part of a group of girlfriends, because she was able to communicate with the other girls and vice versa, as needed. She went straight from preschool into elementary school with the same classmates, so the relationships got stronger instead of getting cut off. Only eight kids from Zuzana's class went on to the same middle school, but her amazing teaching assistant Jiřina helped her overcome any shyness due to the new environment and new classmates. Jiřina went with her through high school as well, where Zuzana didn't know anybody at all, although her new classmates ended up being amazing and communicative as well.

We decided to pursue high school (which is optional in our country) to give Zuzana time before having to enter the "real world" and attempting a vocational school. It didn't matter what she knew how to do, but who she was inside. And Zuzana was still too delicate inside. So she continued through high school in a more familiar learning environment. She kept on learning with her IEP and her assistant Jiřina. She was happy with the other students, and I think that for the first time in her life she felt proud of herself for being able to attend a school like that. Her teachers were incredibly helpful and accepting and tried to support her in everything she did. Four years passed quickly, and at her senior prom she danced with her classmates, wore an evening gown, walked down the red carpet and got the graduation sash from the school principal... I see it as a miracle, a gift from

God for Zuzana. She graduated from high school with an exam in literature, English, biology, and geography.

Our plan to give Zuzana four years of personal growth paid off. She has matured a lot and is currently enrolled as a first-year student in a decorating program. Classes have been all online since November, which she is not thrilled about since she got lucky with great classmates once again. They are sweet girls with big hearts and they love Zuzana's assistant Jiřina too. After the first semester Zuzana was on the honor roll even without an IEP, only with a lower number of hours, but the coming weeks will tell – the school really is not inclined to or equipped for inclusion and that does not appear likely to change in the near future.

We can't wait for Zuzana to be able to go back to where she feels happy and where she always looks forward to going: her drama class, painting with Miss Marta, the gym with her favorite trainer Filip, and traveling with me in the summer visiting castles around the Czech Republic. Plus spending weekends with a few friends from Ovečka (an organization that helps families with children who have Down syndrome in České Budějovice – www.ovecka.eu). This year Zuzana had to make do with online school, occasional video calls with her friends, watching sci-fi movies and rom-coms, reading books, and choreographing her own dances. She loves all these things, and it does not seem that she is bored staying home.

We will see what happens in time. Zuzana would like to work with young children, or she would also enjoy working in a coffee shop, but we still have to make arrangements for that. We are truly relying on God's help and leadership.





Zuzana's artwork

My name is Zuzana,



and I am 23 years old. I live in České Budějovice and I have a sister named Johana (she is a doctor in Orlando, so she doesn't live here with us). I have my friends: Zuzana, Anna, Lenka, Eva and Bára. I used to go to school in Nové Vráto for preschool and elementary school. Then I went to middle school at ZŠ Dukelská. And then I attended the Czech-English High School. I had a beautiful senior prom there. Even my sister Johana came from the USA to see me. Then I had some pretty hard final exams.

In the fall I started my first year as a decorating student. My favorite subject there is math. I really like English. We have a week of practical subjects and then a week of school. I like the practical subjects better, especially calligraphy. I'm learning different painting techniques, making table settings and models of display cases, I made my own "ex libris" (bookplate), we wrap presents, work with natural materials, and all sorts of things. I like my friends at school. I have a personal assistant called Jiřina. She's great. I have a mom who is a piano teacher. My dad is the head of a construction company and he really likes being able to work out in the garden. (Sometimes he goes to Strážkovice for that.) I also go to the gym Pouzar and I have a personal trainer there called Filip. I like painting with Marta and taking piano lessons and going to drama club. I played my graduation concert with Bára. She played violin and I accompanied her on piano. I also like swimming in the summer. I have an aunt Pavla and an uncle Láďa and a distant cousin Markéta.

I love them all.

What should parents prepare for?
What should they know?

Talking with Jaroslav Šturma, clinical psychologist

What should parents prepare for before or after the birth of their child with Down syndrome? What should they know?

Life with a child who has Down syndrome may be somewhat more complicated than with a child who does not. However, it is also a challenge and an opportunity for the family's life and efforts to take them to new places, compared to families without the same challenges. That means that it is not an easy task, but pursuing it faithfully can lead to growth. These parents can learn more about love and understanding than parents of typically developing children. **They learn that life and health are not a right, but a gift.**

Whether the parents know beforehand or only find out once the mother is looking at her baby face to face and the doctor tells her about the possible diagnosis, the most important thing is for the parents to be ready to **accept their child as they are, and to give them the unconditional love they need.** Because that is what is truly the most important, for the child to feel fully accepted even with their differences. If they can do that, the child will learn and develop in their own way and with their own challenges, but essentially the same as any other child.

We should expect the child's development to take longer in some aspects and give them more time. Unconditional acceptance means giving children the time they need and not rushing them or comparing them to some child development milestones we read somewhere. They set their own milestones. The point is that we know where we are on the road we are walking together, and that we monitor, observe, and appreciate the progress we make. Maybe the child's development will not be as fast as others, but there will be progress and we should learn to prepare them, support them, make plans and carry them out, and most of all to take joy in them.

What particular steps can parents take to get ready for life with their baby with Down syndrome?

Most of all, it's about setting your own internal attitude toward your child. You say to yourself: **"You are our child, and we accept you, I accept you (this from the mother, then the father and the rest of the family). I accept you, I say yes to you with my heart, mind and will. I say yes to you just as you are. I will walk with you in love, patience and perseverance. You are the child who was given to me so that I could grow along with you and give you all my love."**

People can find meaning in whatever comes their way. Nothing that happens is meaningless. It means giving **witness to the world that compassion and love have not died out, that they are still around, and that they are stronger than disability or disease.**



Vítek

Vítek – all smiles with a little something extra

It's the middle of the night. Another freezing cold night like we've had for the past few weeks. The last two weeks we've spent in Prague at the neurorehabilitation center. We've been staying with friends who were kind enough to put us up for a while. I'm typing as quietly as possible so I don't wake up my little boy Vítek. He is not concerned about keeping quiet, so he makes little noises while he sleeps. I love moments like this. His snoring fills me with a sense of calm, knowing everything is all right. Knowing he's sleeping soundly. There are plenty of other moments and little things that I love too, of course. But let's start at the beginning...

Vítek is the baby we waited four long years to meet. You can imagine how happy we were to find out we were having a baby. The pregnancy and birth went smoothly with no complications. But then the neonatologist came to talk to us in the delivery room, saying he suspected Vítek might have Down syndrome. In the first few hours we couldn't believe it. Several years ago we lost our first baby with Edwards syndrome in the second trimester. At that time the doctors told us it was random chance, that there was nothing we could have done to influence it, and that the likelihood of something like that happening again was practically zero. My partner and I don't have any genetic problems, so there was no reason we shouldn't be able to have a healthy pregnancy the next time around. Plus all the non-invasive genetic testing we did this time showed no signs of anything out of the ordinary. Despite all that, they confirmed that Vítek has Down syndrome before we even left the hospital and started learning about life with an extra chromosome.

That was two years ago. In that short time all three of us have come a long way. Vítek most of all, of course. If I had known from the beginning how smart and brave Vítek would be, I could have saved myself a lot of unnecessary worry. I'm afraid I believed the neonatologist's negative prognoses about how our boy wouldn't have a good life,

Vítek – all smiles with a little something extra



all the medical complications he would face, and what all he would probably never have the chance to learn. I wish he could see Vítek now. Then he would see how wrong he was, and maybe he wouldn't scare other mothers with his pessimistic warnings.

When I look at Vítek, I don't see Down syndrome. I see a smart little 2-year-old boy who laughs with all his heart. Vítek is totally laid-back and only gets worked up when he's hangry, just like any other guy. He's been walking on his own for several weeks now, exploring the big wide world from this new perspective. And for the last few weeks we've been going nonstop all day. And you know what? We don't mind at all.

I'm grateful that we have a basically healthy child who wants to explore everything all the time and has his own internal motivation, which makes things easier for us. He's always up for mischief, and if we can combine it with exercise or practicing some skill, we're all perfectly happy about it. I admire his persistence. He never lets the first or second failure get to him, and only rarely throws something just because it doesn't work the first time. He's always learning something. He can imitate anything perfectly. This skill has brought us any number of funny moments. For instance, Vítek thinks it's totally normal to bite a roll of tape. He puts it up to his mouth, checks out of the corner of the eye that someone is watching, and if we were more theatrically inclined I'd say he almost over-acts the moment of biting into the tape. All that because one time Mommy was in a hurry and didn't want to go into the other room to get scissors to cut the tape. Vítek was close enough to register that the roll of tape is something we bite into, and that's that.

Vítek is naturally inquisitive and claps at every success. His physiotherapist has strict instructions not to praise him (okay, that's a bit of an overstatement). But he gets so excited when he hears words like "great job!" or "amazing!" that he'll start clapping automatically. Which can be a bit of a problem if his hands are, say, supporting him while he's on an exercise ball. There's no holding back the laughter and joy whenever he insists on getting everyone who was there to witness his success or the reason for the praise to clap for him as well. He turns to each person in turn and claps in their direction like a seal clapping its flippers and he doesn't stop until we show him the proper recognition. It's funny.

He waves at passersby from his stroller when we're out on walks. Most of the time they smile back. He has an incredibly infectious laugh that lifts people's spirits, which makes us feel like Vítek brings people together. He is quite empathetic for his age. Any time we are not in the best mood, he comes over and gives us a hug. Sometimes he runs back and forth between us, showering each of us with kisses and getting so much joy out of it at the same time.

Vítek is an only child, so we don't have any point of comparison for raising a child without Down syndrome. I still know that I wouldn't change a thing. One mom I know said that if there was a cure for Down syndrome, she would never give it to her daughter. And I feel the same. Yes, taking care of a child with Down syndrome certainly has a particular set of challenges and in some ways it may be harder than raising a typically developing child, but it has so many upsides as well. You learn an unbelievable level of tolerance and patience. Speaking for myself, I'd say that I live more in the here and now and I've learned to take more joy in the little things in life. Down syndrome is part of Vítek. It's just one piecpiece of the puzzle that makes up our amazing little boy whom we love more than anything.

The Jérôme Lejeune Foundation explains: What is Trisomy 21?

"Life begins when all the necessary and sufficient information is combined in such a way that a new being comes into existence. This occurs precisely at the moment when all the necessary information carried by the sperm combines with the information carried by the egg. When the sperm penetrates the egg, a new being is created. Not a theoretical human, but a real being whom we will later call Peter, Paul, or Mary."

Professor Jérôme Lejeune

What is Trisomy 21?

The name "Trisomy 21" was proposed in the 1960s by Professor Jérôme Lejeune and later approved by an international group of scientists. It refers to the set of physical and biological phenomena caused by three copies of chromosome 21 instead of two.

Humans usually have 46 chromosomes. Chromosomes – structures present in the nucleus of the cell – contain the set of inherited traits for each individual and are primarily composed of deoxyribonucleic acid (better known as DNA) and proteins.

These chromosomes are divided up as follows:

- **44 chromosomes (also called autosomes) organized into 22 pairs that are the same for both sexes.** These pairs, numbered 1 to 22, do not carry the genes that determine biological sex (a gene is the smallest unit of genetic information). They are organized by size from largest to smallest. Chromosome 21 thus falls into the 21st pair.
- **2 allosomes (chromosomes that determine biological sex):** XX for female and XY for male.
- Three copies of chromosome 21 instead of two causes an excess of the genes carried on this chromosome (about 255) and thus affects how the entire organism functions.

What is the cause of Trisomy 21?

Trisomy 21 is a genetic deviation that affects the individual as a whole. It is caused by a chromosomal anomaly: usually humans have 46 chromosomes organized into 23 pairs. People with Trisomy 21 have three copies of chromosome 21 instead of the usual two, meaning they have **a total of 47 chromosomes. Chromosome 21 is the smallest chromosome**.

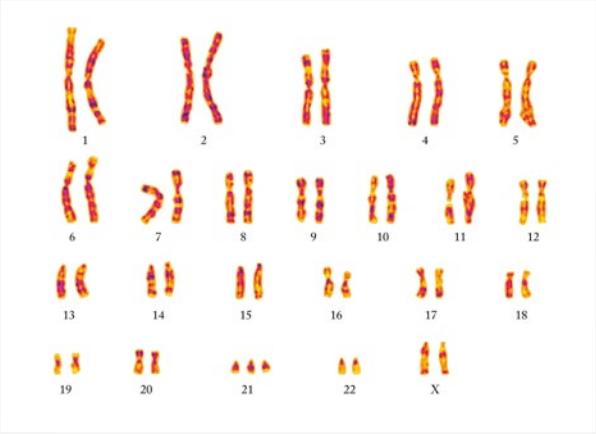


*Image of the **chromosomes of a girl** with Trisomy 21 (CASASSUS, 2014)*

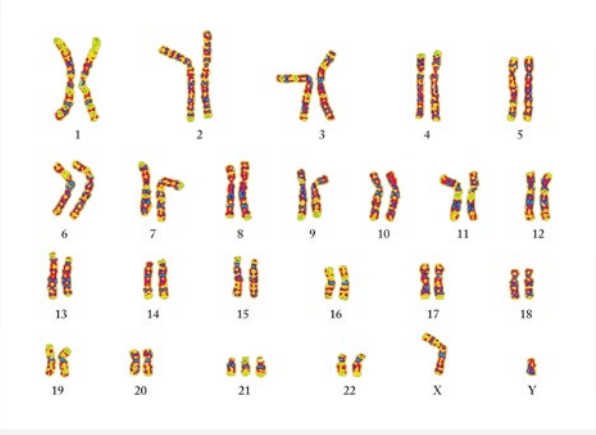


*Image of the **chromosomes of a boy** with Trisomy 21 (SCIENCE PHOTO LIBRARY, 2021)*

The Jérôme Lejeune Foundation explains: What is Trisomy 21?



We can compare this genetic deviation to a computer with too many applications open at once. The computer is not broken, it still works, but it runs more slowly because it can't process all the information at once. We need to close some windows so that the computer can run at full speed.

Researchers are working on suppressing this excess information in patients by blocking some of the unneeded genes coming from the extra 21st chromosome.

Is Trisomy 21 a disease?

In the sense that a disease involves damage to the health and function of a human being, yes. More accurately, Trisomy 21 is a condition or a syndrome in which the presence of an extra chromosome causes characteristic organic and functional disorders that combine together and have a certain development.

On the other hand, the word *disease* implies the possibility of medical intervention and treatment. That would be misleading and could give false hope with regard to Trisomy 21. That is why Jérôme Lejeune preferred to use the term *"a disorder of cognitive abilities"*, that can be improved with exercise and regular practice.

Is Trisomy 21 a congenital defect?

A congenital anomaly is an anomaly that is present at birth regardless of the cause (inherited, viral, toxic).

Trisomy 21 is a constitutional disorder because it is connected to a particular congenital body frame and mental structure, in this case caused by a third copy of chromosome 21.

This constitutional disorder can include:

• congenital deviations that may or may not cause develop-

mental defects such as cardiovascular disease, digestive tract disorders, and congenital cataracts,
- health problems that occur during the person's lifetime, such as thyroid problems, Celiac disease, leukemia, epilepsy, and keratoconus,
- intellectual disability.

These symptoms of Trisomy 21 may not all be present at birth; some may never appear and some may develop over time. That is the reason for regular medical supervision by experts who know which anomalies can be expected at what ages.

Why is it called Trisomy 21?

Professor Jérôme Lejeune proposed ***Trisomy 21*** in place of the name *Down syndrome* (as well as the racist term *Mongolism*) as they were inaccurate on three levels:

- **Historical:** John L. H. Down was not the first person to describe the syndrome. He was preceded by French physician Édouard Séguin and French psychiatrist Jean-Étienne Esquirol, who was the first to clinically document, in 1838, a case of Trisomy 21, theorizing that the skin of people with Trisomy 21 has the texture of flour.
- **Scientific:** this deviation is not caused by some "regression to a primitive race" or "regression to archaic forms of man," as John L. H. Down believed, but the presence of an extra chromosome.
- **Ethical:** John L. H. Down assumed that Europeans were a "superior" race. In addition to the "Mongol regression," he also described Ethiopian and Malaysian "regressions."

What is the risk that I will have a child with Trisomy 21?

Trisomy **21 is the most commonly diagnosed cause of genetic intellectual disability:** this anomaly appears in an average of 1 out of every 700 to 1000 babies around the world.

Any woman can have a child with Trisomy 21. In most cases this genetic anomaly is not hereditary. The risk of conceiving a child with Trisomy 21 increases with maternal age. A woman has a lower risk of conceiving a child with Trisomy 21 at the age of 20 than at the age of 40.

Forms of Trisomy 21

There are multiple forms of Trisomy 21.

1. Simple Trisomy 21 (non-disjunction)

The most common form, accounting for about 95% of all cases. It has three characteristics:

- **Free** (as opposed to translocation): all three copies of chromosome 21 are free and not attached to each other.
- **Complete** (as opposed to partial): the trisomy affects the entire chromosome 21.
- **Homogenous** (as opposed to Mosaic): Trisomy 21 is observed in all cells tested (10, 20 or 30 cells depending on the laboratory). The term homogenous does not exclude the possibility of Mosaicism in other cells of the body.

2. Translocation Trisomy 21

The karyotype has two free copies of chromosome 21, with a third attached (translocated) to a different chromosome.

3. Partial Trisomy 21

Only part of chromosome 21 is duplicated during the cell division process. In that case, which is quite rare, the symptoms and severity of the disability will depend on the particular section of the chromosome that is doubled.

4. Mosaic Trisomy 21

Cells with 47 chromosomes (three copies of chromosome 21) exist alongside cells with 46 chromosomes (two copies of chromosome 21). The proportion of the two types of cells depends on the time at which the deviation occurred. It differs a great deal from person to person, organ to organ and tissue to tissue.

How does Trisomy 21 manifest?

Every person with Trisomy 21 is unique and the excess genetic information appears differently for everyone. Some signs are common to all patients, although the degree to which they appear can differ significantly.

The most noticeable ways Trisomy 21 manifests are the characteristic physical features and varying levels of intellectual disability, especially affecting the ability to think abstractly.

The Jérôme Lejeune Foundation explains: What is Trisomy 21?



The varying degrees of intellectual disability can be explained partly by the usual range of IQ, which can vary widely in the general population. In other words, despite common misconceptions, **Trisomy 21 does not have multiple degrees of severity**.

Trisomy 21 can also be accompanied by other congenital complications, some apparent from birth (heart or digestive tract defects) and some that arise during the individual's lifetime (endocrinal, orthopedic, vision and hearing problems).

Most of these complications can be treated, so timely diagnosis is key to giving people with Trisomy 21 the best possible quality of life. Specialized medical supervision as recommended by the Jérôme Lejeune Institute is therefore both essential and highly beneficial.

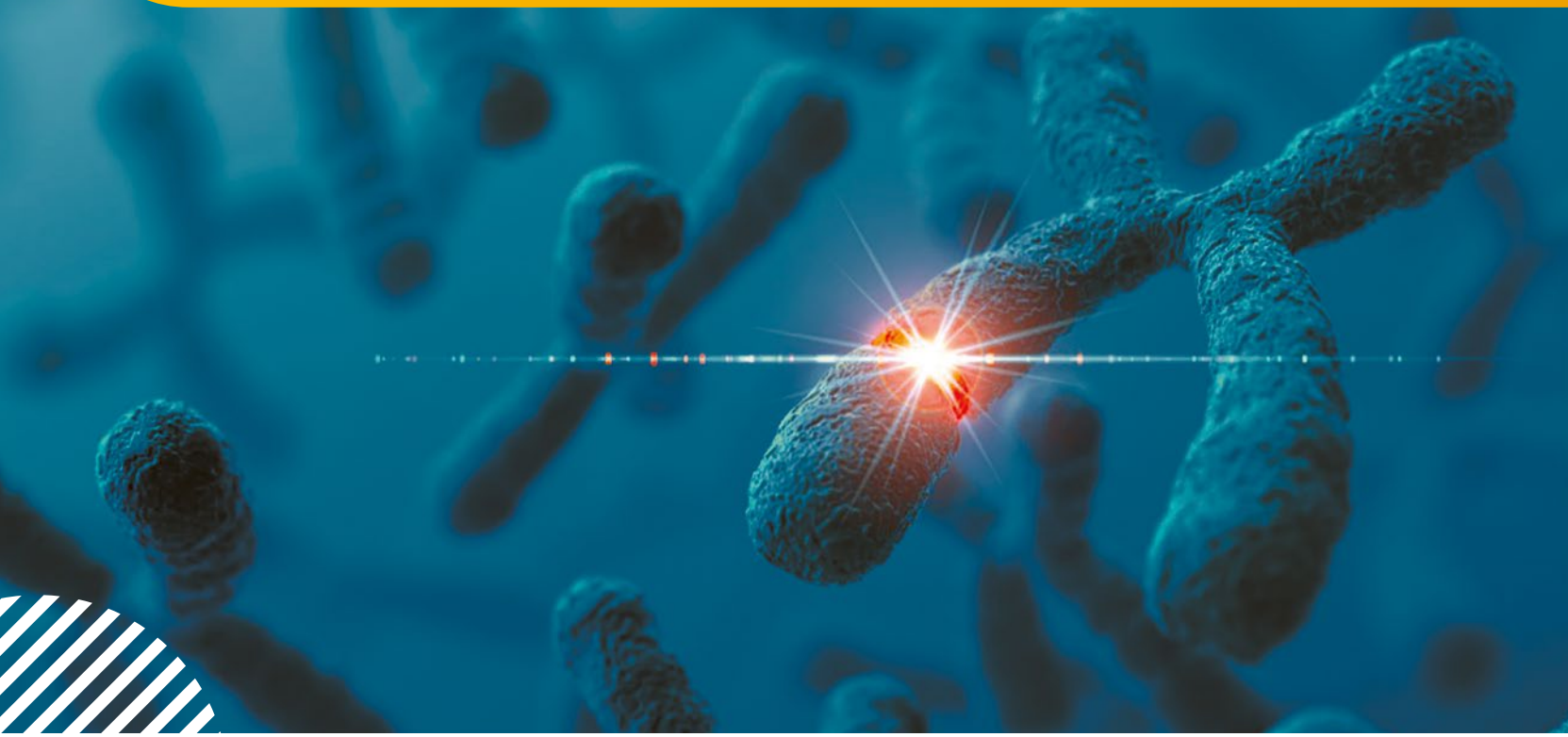
The same applies to other specialized therapies (physiotherapy, speech therapy, development of cognitive function), which help children develop their abilities as much as possible, engage them in the educational process according to their individual ability, and thus give them as much independence as possible. Incidentally, improving medical care and better access to therapies have increased life expectancy in Trisomy 21 patients significantly, bringing it closer to life expectancy in the general population.

Will there ever be a medicine for Trisomy 21?

Medical treatment and rehabilitation can correct or eliminate many of the complications associated with Trisomy 21, such as heart and digestive tract defects, hypotonia, and orthopedic, vision and hearing problems.

With respect to the intellectual disability that is the primary obstacle to people with Trisomy 21 living a fully independent life, current medical research indicates that improvements can be made in this regard as well.

Sources: HUNTINGTON, 2004
JÉRÔME LEJEUNE INSTITUTE, 2021
ŠUSTROVÁ, 2004.



Genes and Chromosomes

Down syndrome is a congenital anomaly. That means it is present at birth, usually from the moment of conception. Down syndrome is caused by an extra copy of the 21st chromosome.

Chromosomes are molecules of deoxyribonucleic acid (DNA) that are present in the nucleus of every cell in the human body. They carry a record of all the traits and characteristics we have inherited from our parents. This record takes the form of encoded messages (genes) in the structure of our DNA. Every chromosome is made up of one molecule of DNA. Every cell in the human body has 23 pairs of chromosomes, making 46 total. Based on international consensus, the chromosomes are numbered in order of size from 1 to 22. The final, 23rd pair contains the biological sex chromosomes XX and XY.

Down syndrome occurs when an individual has a complete or partial extra copy of chromosome 21. This means the 21st pair of chromosomes has three chromosomes instead of two, which is why the condition is called Trisomy 21.

Sources: BAILEY, 2021
JÉRÔME LEJEUNE INSTITUTE, 2021.

Professor Jérôme Lejeune

(13. 6. 1926 – 3. 4. 1994)



"Life has a very long history, but each of us has a very precise beginning, and that is the moment of conception."

June 2026 marked the 100th anniversary of the birth of Jérôme Lejeune, the French physician and geneticist who discovered the cause of Down syndrome and became one of the greatest defenders of children and adults with Down syndrome. He was a devout Catholic who saw his roles as scientist and physician as perfectly aligned with his faith.

Jérôme Lejeune is known primarily as one of the founders of the field of modern human genetics and medical genetics. Even before his discovery, however, he had an extraordinary affection for children with intellectual disabilities and developmental disorders. He had a particular tenderness and understanding for children with Down syndrome, pointing out their extraordinary gifts and positive characteristics. As a young doctor he saw the suffering these children experienced being excluded from society and the prejudice their families experienced from people around them. Medical science at the time was not able to help these children and their families, which led Lejeune to dedicate his life to doing just that. He later said that he never would have achieved those results if he had not been motivated by the love the parents felt for their children. He strongly believed that **no disability can limit the ability to love**. Thanks to his reputation as a professional and stories of his kindness and genuine care for children, thousands of families came to see him with their young patients and Lejeune assured each that with the right guidance and loving environment, their child could fully develop their potential and live a happy life.

Jérôme Jean Louis Marie Lejeune was born on June 13, 1926 in Montrouge (formerly a suburb of Paris). He came from a well-to-do family that lost all of its wealth during WWII. Jérôme was the second of three sons. He wanted to become a doctor since childhood. Originally he wanted to be a surgeon, but instead he became a scientist. After completing his studies at the Paris School of Medicine, Lejeune decided to narrow his pediatric focus to working with children with intellectual disabilities. He quickly became a world-renowned expert in the field, centering much of his research around Down syndrome, the most common diagnosis.

In 1958 he identified the cause of Down syndrome as an extra (tripled) chromosome, later specified as chromosome 21 (trisomy 21), making him the first doctor to prove a connection between a genetic anomaly and intellectual disability. His discovery proved that a child born with Down syndrome was the result of a genetic lottery with no direct external cause. Until that point, Down syndrome had been incorrectly considered "racial degeneration." English physician John L. H. Down described the characteristics of people with Down syndrome in 1862, and the syndrome came to bear his name. Almost a hundred years later, Professor Lejeune discovered the cause and developed methods of diagnosing the chromosomal anomaly during pregnancy. Later Professor Lejeune and his colleagues discovered the mechanism for other chromosomal disorders as well, paving

the way for cytogenetics, modern genetics, and prenatal diagnostics. Under his leadership (from 1964) the cytogenetics department at the Hôpital Necker Enfants Malades in Paris became one of the most active in the world. There his team studied about 30,000 chromosomal cases and examined more than 9,000 patients with genetic conditions. Lejeune's primary interest was to find a way to heal these people coming to him from all over the world.

His work describing the discovery of Trisomy 21 was published in 1959. He married Danish-born Birthe Brigsted, whom he met during his studies, the same year. They had five children together, two sons and three daughters. He loved his family more than anything and always made time for his children, even at the peak of his career. His wife Berthe supported him throughout their lives.

In 1963 Professor Lejeune became the first to describe and diagnose cri du chat syndrome (cry of the cat, also known as Lejeune syndrome), and a year later became the first professor of fundamental genetics at the Sorbonne school of medicine. In 1969 he became the first and so far the only French winner of the prestigious *William Allen Memorial Award*, granted for research in human genetics.

While his research (analyzing the biochemical processes that occur in Down syndrome patients) aimed to find treatments and ways of improving patients' lives, minimize the negative impact of their disability, and find effective therapies, most of his colleagues chose a quite different path. In direct conflict with his efforts, the results of his work were used to detect Down syndrome as early as possible and terminate pregnancies for the purpose of eugenics. Jérôme Lejeune found this incredibly upsetting and sharply criticized this behavior as a breach of the principles physicians should hold sacred. He decided to defend his youngest patients in public. The obligation he took on to defend those among the most rejected in our society led to influential and highly placed people turning away from Lejeune, yet also strengthened the love from the patients he loved so much.

Professor Lejeune became one of the most significant leaders of the pro-life movement. He testified on its behalf as an expert witness in court and before congressional committees, and spoke in public as well as in media debates. He defended human life as a unique gift from conception to its natural end. His commitment to the cause made relationships with certain colleagues difficult, although he outpaced them in arguments, renown and the significance of his discoveries. When he spoke at a genetics conference in the USA in defense of unborn children and against the legalization of abortion, stating that an embryo is a person, he received only silence and ridicule. As he wrote to his wife, he "lost" his Nobel Prize by doing so.

Lejeune led a campaign at his wife's behest against a 1973 bill proposed to the French Parliament to decriminalize abortion, gathering signatures from physicians and other experts on a petition that ultimately led to the bill failing. The law passed quietly the next year, however, as did similar laws in many other European countries.

Lejeune had a close personal and professional relationship with Pope John Paul II, who made Lejeune his medical ethics advisor. In 1974 Professor Lejeune became a member of the Pontifical Academy of Sciences. In 1981 he was appointed to the Académie des Sciences Morales et Politiques and in 1983 to the Académie nationale de médecine.

In 1993 he was diagnosed with lung cancer and in 1994, despite his worsening health and terminal diagnosis, he accepted the appointment from John Paul II as first President of the Pontifical Academy for Life, which became his spiritual legacy in protection of human life. In spite of all that, however, Jérôme Lejeune died knowing that his research had led to a completely different outcome than he had intended: ***"I was a physician who should have cured them. Now that I am leaving, I feel that I have contributed to their condemnation."*** Shortly afterwards, Professor Lejeune died of cancer at the age of 67 on April 3, 1994 (Easter Sunday) in Paris.

Sources: DĚDKOVÁ, 2004
FONDATION JÉRÔME LEJEUNE, 2021
KOPECKÁ, 2017
SÁŘIN HLAS, 2020.



Bernadeta

The Song of Bernadeta

Bernadeta is our much-wanted fifth child. Everything was different with her from the very beginning. While I was expecting, I couldn't even see a drop of coffee or alcohol. I ate mountains of radishes and drank bitter grapefruit juice. The little one inside me kicked only very slightly, but it filled me with joy and a strange protective tenderness. Even the childbirth was different, no complications at all. The doctor who delivered the baby congratulated me, but...Our amazing little baby seemed so fragile, like a rag doll.

If I had known then what strength she had in her and what she would teach us, I could have spared myself some pain and ignored the "concerned" advice and criticism from some of the medical staff. But no one can predict the future, and no one knows what potential a helpless little baby like that might hold.

My husband and four older children accepted Bernadeta immediately with love and without reservations, just as she was, which when I look back at it seems like the most important and decisive moment that gave us a good start in our new life.

"May your love always be greater..." said the priest when he came to the hospital to baptize Bernadeta several hours after she was born.

"You have to love her all the more," my mother encouraged me over the phone while I was still in the hospital.

"See how she's looking right at your face," the pediatrician pointed out to me on our first visit.

"Oooh, what a beautiful baby girl..." exclaimed the doctor at orofacial therapy. "You'll raise her just the same as your other children, just give her a lighter load."

"It's easy to love Bernadeta," her godfather Jakub confessed to me.

I carry those words with me everywhere. The incredible support from our family, godparents, friends, and the professionals guiding us along the way led to major shifts



in our life priorities, certainties, relationships, and work on ourselves.

That acceptance and love is still with us today, here and now, when we need it. We take things step by step and go at her (and our) own pace. Bernadeta's siblings also became her friends and natural therapists, which does sometimes involve a certain amount of sibling disagreement, scuffles or teasing. Bernadeta is gradually opening up the wealth that is in her and acting as a therapist for us.

She's in elementary school now. Learning is more challenging than usual with her, because I have to be really present, in body, mind and heart. Because she struggles with abstract thinking, especially in math, she comes over to snuggle, get hugs, and build up the courage to keep going. That is one of the advantages of homeschooling, because it usually does the trick. She takes joy in everything she has learned and seems to put every bit of it to use in everyday life.

She has her own distinctive sense of humor and often wears a huge smile on her face with a dimple on her cheek. I'll never forget how she hid all three school books in the laundry hamper one day when she didn't want to learn to read. Or the winter's day she tried to convince me to go to the grocery store. I said it was cold and I wanted to go home because it was warm at home, and she promptly responded, "It's warm in the grocery store, too." As she likes to say, "I don't have a hundred fingers!" (The rest of us say "I don't have ten hands!")

She is a gracious hostess who greets family members and guests, involves them in her favorite games, and accompanies them to the door when they leave. She loves watching cartoons and children's movies, swimming, exercising, dancing, reading, singing, and she's learning to play the recorder.

Most of all, she is here with us, for us, and we are happy that we have her.

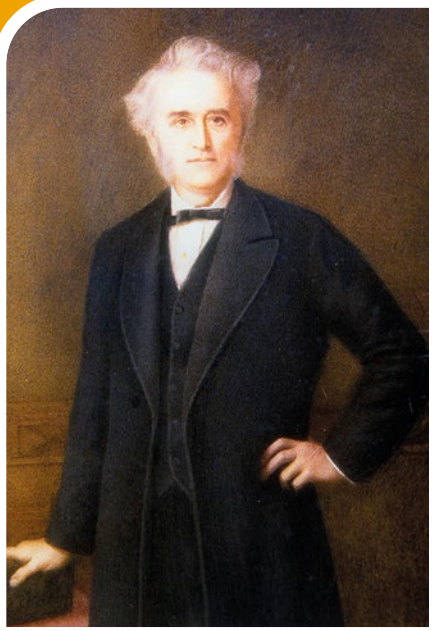
In the world of music

Jana Hamouzová, music teacher

Bernadeta is quite self-assured in her pure, open, fantastical world. I wish I could act with that kind of self-assurance myself. She runs into the classroom in excitement, puts her things in their usual place, tells me what is in her backpack, pulls out her recorder, and we can start playing. She can say what she needs and what she would like to do. I'm happy to see that Bernadeta can stay in the world of music for the whole lesson. We often play breathing exercises and tone development exercises. We also play folk songs, some well-known and some less so. First Bernadeta can sing the song, then play it on the recorder, on her own or accompanied by the instrument of her choice, or else she can simply listen to new songs. Bernadeta always comes to class prepared and has a good memory for songs. I would like to keep enjoying the time I spend teaching this little girl and I want to see her happy, so I think it is well worth continuing in what works for us.

Dr. John Langdon Haydon Down

(18. 11. 1828 – 7. 10. 1896)



John Langdon Haydon Down was an English physician, psychiatrist and neurologist who gave his name to Down syndrome (the chromosomal anomaly Trisomy 21). John Down described the syndrome, but the cause was discovered a hundred years later by Prof. Jérôme Lejeune. Today Dr. Down is recognized as **a pioneer in ergotherapy and a proponent of education for people with intellectual disabilities**. He argued that all children with disabilities should receive an education and support regardless of their social background to allow them to participate in society. This put him many years ahead of his time.

John Down was born on November 18, 1828 in Torpoint, Cornwall, as the seventh and final child in the family. As a child from a large family, at 14 he began working as an apprentice in his father's apothecary shop. While working there, at 18 he met a girl with intellectual disability, and the meeting stayed with him and awoke in him a desire to do something to help people like her.

The first step on his way to a medical education was working as a physician's assistant in the East End Hospital in London. Later he enrolled as a student at the Royal Pharmaceutical Society. After passing two important professional examinations, John Down returned to his home town and worked in his father's apothecary shop preparing medicines. In 1853 his father died and John Down began studying at the London Hospital Medical College. He was an excellent student and in his final year won the prestigious gold medal in general medicine, surgery and obstetrics. While in London he lived with his sister, who was married to a man named Philip Crellin. When John met Philip's sister Mary, he fell in love with her, and they married in 1860. Mary stood by his side for the rest of their lives and helped him make his visions reality. They had four children together.



After completing his studies in 1858 John Down had the opportunity to begin an academic life with his professor's support, but instead decided to enter practice in the Earlswood Asylum Complex in Surrey, which housed over 400 people with intellectual disability. The people living in the asylum at the time had very poor prospects indeed. Unsanitary conditions, diseases like typhus and tuberculosis, and dismal living conditions led to high mortality rates and premature death even from simple infections. Down's religious convic-

tions, strong sense of compassion, and ability to inspire others led to him being appointed head physician even though he was a new graduate and had no experience working with patients of this type.

John Down had a keen eye for detail, noting differences and specific traits in his patients with varying degrees of disability. As a result he had soon (in 1862) identified and described a group of patients with what we describe



today as Down syndrome. His ethnological classification of people with intellectual disability was based on the incorrect assumption, influenced by Darwin's writings, that the deviation was caused by a "regression." At that time many believed that Europeans were "superior" to other races like Mongolian, Malaysian, and Ethiopian. (Additionally, John Down was not the first to describe the syndrome. He was preceded by French physician Édouard Séguin and French psychiatrist Jean-Étienne Esquirol, who was the first to clinically document, in 1838, a case of Trisomy 21, noting their tendency to have "floury" skin.) Down dedicated himself fully to his patients, taking part in their daily lives and soon observing that they had a particular empathy, a great sense of humor, and the unusual ability to mimic, and that they could learn any number of skills with support. He also discovered that, while often difficult to understand, their speech was comprehensible and that regular exercise could improve comprehensibility even further. Down's wife Mary used her organizational skills to help him run the asylum. She arranged interesting activities for patients and, since she was musically gifted, also taught some of them to play the piano.

In 1868 Down resigned from his position at Earlswood and purchased a family estate in Teddington near London, expanding it over time with donor assistance and turning it into a home for children with intellectual disability. He named the estate Normansfield after the donor who helped him implement his plan.

Normansfield began with about twenty patients. It had well-equipped, spacious living areas and excellent sanitary facilities. The first inhabitants were children from wealthy families who could contribute to the costs of running the home. At Normansfield children learned practical skills as well as basic literacy. The estate also had workshops and farm buildings with horses and farm animals as well as fields and gardens. Residents learned to grow vegetables, care for animals, and engage in physical recreation such as riding horses, cycling, skating, and dancing. Others enjoyed handicrafts that we would today call therapy. Down established an amateur theater in which his wards took part. The favorable conditions at Normansfield allowed residents to lead dignified lives and have longer lifespans than people in other institutions. The facility employed qualified staff members and teachers. Normansfield became a highly sought-after institution and by 1891 it had about 150 patients.

Dr. John Langdon Down died at the age of 67 on October 7, 1896 in



Teddington. His sons Reginald and Percival, both qualified physicians, ran the institution after their father's death. Reginald's son was born with Down syndrome and lived a long and happy life at Normansfield, where he died at the age of 65.

Sources:
GRZYBOWSKI and ŻOŁNIERZ, 2021
KOPECKÁ, 2018
LANGDON DOWN MUSEUM, 2021.

The Paradox of Today's World

Talking with Jaroslav Šturma, clinical psychologist



On the one hand, our society is learning to be more tolerant towards people with disabilities. On the other hand, a very high percentage of pregnancies are terminated due to congenital developmental defects. Is this not something of a contradiction? We learn to accept people with disabilities while at the same time rejecting them?

We are setting up an artificial boundary here. Not only in my view, but according to the findings of modern embryology and developmental psychology, a person is a person from the moment of conception. We convince ourselves that if we agree on some set time – three months, for instance, or if prenatal diagnostics indicate some disability even later – after which we will not allow the child to live, that it will somehow "help" us confront the problem. But the opposite is true: it only helps us avoid the problem, avoid the confrontation. It is essentially running away from the problem. And we believe, and I myself believe, that in the future it will be more and more clear that someone conceived as a human should be born as a human, and live a dignified life with love, in love and for love, and eventually leave this world in the same way.

Many mothers can confirm from their own experience that if a mother decides not to have genetic testing, or if she knows she is expecting a child with some disability and decides to keep the baby anyway, the pressure to reject her child becomes intense, especially from healthcare professionals and geneticists. Support from society in general is no better in this regard.

The idea that a person is a person starting at conception is not a matter of scientific debate. Everything else that is under discussion or debate is ideology, maneuvers, defensive mechanisms on the part of individuals, legislators, or humanity as a whole in order to run away from the problem, all at the expense of the most vulnerable person involved: the baby. But I believe that humanity is making progress here as well. I believe that it is a matter of time before it is obvious that human life at every stage is a gift and there can be no discussion over whether to let it live or not. Our task is to support life.

This philosophy and approach to life has far-reaching consequences. The mentality we are talking about means that we bury the problem into some underground river and for a while we don't see it, but then it pops back up at the end of life in the form of euthanasia and our unwillingness to care for people experiencing old age or illness until the very end. Those are absolutely two sides of the same coin. The answer of how to treat people leaving this world, such as people with Alzheimer's, ties into this attitude closely: the position you take on the life of the unborn is the position you take on the life of someone experiencing illness, old age, or disability.

Photo source: HÁJEK, 2021.



More Than Just an Extra Chromosome

Zuzka Šimonová

When we finally had our long-wanted baby two years ago, my partner and I thought that nothing and no one could ruin our joy in finally being a family. We were wrong. Due to oxygen deprivation, our son Vítek was immediately placed in an incubator when he was born so he would be under medical supervision. While we were still in the delivery room, the neonatologist informed us of his medical condition. He was the first person to voice the suspicion that Vítek had Down syndrome. I can still remember hearing his words like they were coming from far away. All I could think about was wanting to have my son with me. To be the first to see him, the first to hold him. Instead, we kept hearing unfamiliar terms like trisomy and hypotonia. The doctor was like the evil godmother in some fairytale. He destined Vítek to all sorts of diagnoses and health complications. He threw around words like mental retardation, inability, lack of independence, apathy… Before I had even had the chance to see my son, I heard from the doctor all about what he would be like, what all he would never be able to do, and what all he would never learn.

It was like they put this huge imaginary bucket next to Vítek right there in the delivery room. Very soon it started filling up with all sorts of predictions and prophecies. For a long time we were bitter about the way the diagnosis was shared and later confirmed with us. No mother wants to hear "IT didn't work out this time" said about her much-wanted baby. My

partner and I view doctors and all healthcare professionals as authority figures. We try to trust them, partly because a few years ago they saved my life. Besides, putting yourself in the care of a doctor you don't trust just doesn't make sense. That's why we took their words, however painful, as an absolute and unchangeable truth.

Fortunately, that only lasted a short time. The thing that helped us most was spending time with our baby and falling in love at first sight. Within the first several days and weeks we learned to orient ourselves in the world of extra chromosomes. We got a lot of information and most importantly met doctors, therapists and experts who had more relevant information about children with Down syndrome from working with them and seeing how families in the same situation really work. Meeting other families and having sessions with an early intervention specialist also helped us a lot.



As we learned to accept the diagnosis and reach something you could call coming to terms with it, we started pouring the negative and untrue things out of that imaginary bucket. And with slow but joyful baby steps we began to fill the "bucket of prophecy" with more important and true things. Now our bucket is full and even over-flowing. Sure, somewhere down there are a few spoken and unspoken worries. But that's part of being a parent. We know those worries are unnecessary. All they do is keep us on guard.



Looking back, I think about how many tears, how much suffering and pointless worrying I could have saved myself if I'd known then what I know now. If I had politely declined that imaginary bucket and only accepted my baby. To be quite honest, and you can believe me or not, in the past two years with my son, there's not a single second that I regretted that he has Down syndrome. Yes, there have been challenging moments and there will continue to be. There have been situations that made me cry, but none of them involved regret at Vítek's diagnosis. It was always about uncertainty, fear of the unknown, whether we would be able to handle caring for and raising a child with Down syndrome. All of it stemmed from our lack of knowledge and the distorted and incorrect preconceptions that we had ourselves or that someone talked about after our baby was born.

Families who are expecting or have just given birth to a baby with Down syndrome are often (although not always) presented with highly misleading information that only causes them unnecessary distress and hits them in their most sensitive places. Moments like this sow a seed of underestimation in parents. Underestimation of themselves, their partners, their relationship, and especially their little ones. Ask any parent of an older child with Down syndrome and I'm sure they will tell you that they have underestimated (or perhaps still underestimate) their child in certain skills or abilities.



And yet a few small changes make all the difference. Parents need to receive words of encouragement along with the relevant information from their doctors. Let's change that underestimation to **encouragement**. Let's encourage parents to care for their children in an environment full of acceptance, understanding, and (most of all) love.

I wish all doctors, therapists and other experts could see our little boy. I fully believe they would reconsider their dire prophecies. I wish all parents thinking about whether they can handle caring for a child with Down syndrome could see how other families in their situation really live.

Other than that extra chromosome, Vítek is a completely healthy boy. Immediately after he wakes up next to us, he smiles, hugs us, and gives us a kiss. At 2 years old he is walking, riding on his balance bike, and kicking a ball just like the other boys. He understands everything we ask him to do. He knows most of the most common animals. He loves to listen to music and dance. He comes up with all sorts of silly ideas and laughs at them in glee.

Now I look back and smile at the thoughts that ran through my head when he was born. When I look at my son, I don't see Down syndrome. I don't see the apathy someone mentioned way back when. What I do see is an incredible amount of empathy. I often think back to a post on an online forum I once read. Some mom wrote that she would never want to have a child with Down syndrome, because she would be ashamed of the child and would have to go around with the stroller covered so no one would point at them. I think about that whenever Vítek and I go out with the stroller. He always smiles and waves at people while we're walking, and it really does warm my heart. I can see how many people he cheers up and brightens their day. And that's no small feat for a 2-year-old, especially these days. Vítek's smile and positive energy actually made him the face of a media campaign by a local foundation. Photographs of our little boy regularly appear at public transport stops and public areas around Prague. We don't have to be ashamed of him or feel sorry for him or ourselves. He is not an advertisement for anti-social behavior, suffering, or aggression, like they said he would be. I adore every little thing about him, whether it's because of his extra chromosome or not. Vítek is everything a parent wants in a child, full of joy and warmth.

What We Would Like to Hear

Rick Smith, proud father of Noah

Dear OB/GYN,

I'm the father of a two year old boy named Noah who was born with Down syndrome, and whom we love very much.

My hope in writing you this letter is to tell you some of the things I wish I would have known the day we found out our son was born with Down syndrome. Our son did not have a prenatal diagnosis of Down syndrome, and our amazing pediatrician did a great job of calming our fears, honoring the life of our boy, and letting us know we were in this together. However, as you'll read below, our interactions with our OB/GYN were not as positive.

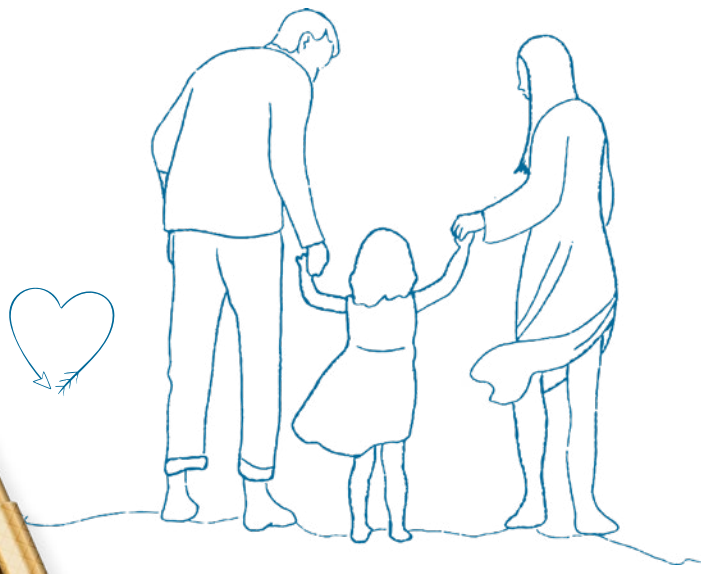
As an OB/GYN you will likely be the person who delivers the prenatal diagnosis of Down syndrome. Hopefully this letter will help you to deliver a Down syndrome diagnosis to your patients in a way that honors the child, and gives parents hope and encouragement.

As the first point of contact for a new parent of a child with Down syndrome, you have a lot of influence and authority. Those parents are going to be clinging to every word you say, and watching every facial expression that comes across your face. How you deliver the Down syndrome diagnosis to those parents could be a matter of life and death, literally.

When our son Noah was born, my wife's OB/GYN's first words to us were "I'm so sorry" followed by "Would you like some antidepressants?" We were scared, anxious, and worried; the last thing we needed to hear from a medical professional was "I'm sorry." And my wife certainly didn't need antidepressants.

But our story isn't unique. In fact, I've heard from countless parents of children with Down Syndrome whose OB/GYN did a poor job of communicating to them their child had Down syndrome, or even worse tried to convince them to "terminate the pregnancy." Sadly, a lot of parents take their OB/GYN's advice and abort their child.

Please provide parents with true, accurate, and up to date information about Down syndrome.



Five Ways to Properly Deliver a Down Syndrome Diagnosis

Rick Smith, proud father of Noah

1. Say "Congratulations," not "I'm sorry"

It doesn't matter if the child is diagnosed with Down syndrome prenatally, or after birth (as in the case of our son), always congratulate the parents for the child they have conceived, or the child that was just born. The birth of a child always calls for congratulations.

2. Keep a positive demeanor

You're about to have an awkward conversation with some parents, and you have no idea how they're going to respond to what you're about to tell them, but please stay positive. You're talking about someone's child. You're the professional and the parents are going to follow your lead.

Please get over your fear and nervousness, put a smile on your face, and tell them that their new little one has a surprise for them, then help them understand what causes a child to be born with Down syndrome. This is important as some mothers think it's their "fault" that their child has Down syndrome, and that they may have done something wrong to cause it.

3. Tell them there's never been a better time in the history of the world for a child to be born with Down syndrome

There's a good chance that you don't personally know anyone who has Down syndrome, and an even better chance that you aren't up to date on the current information about what life is like for children with Down syndrome.

The truth is, there really has never been a better time in the history of the world for a child to be born with Down syndrome. Now, there are countless resources available to help people with Down syndrome reach their full potential. Today people with Down syndrome go to college, have careers, drive, get married, are public speakers, become actors and actresses, play (multiple) musical instruments, live independently, and live meaningful and productive lives.

In fact, American Journal of Medical Genetics recently published a study that showed that parents of a child with Down syndrome have a more positive outlook on life because of their child with Down syndrome. In other words they are happy (not sad and depressed) because of their child with Down syndrome!

It's important that you paint an accurate picture of what their new child's life could possibly be like, and **an accurate picture is a hopeful one**. When you took the Hippocratic Oath you swore that you would use your power (and influence) wisely. That little baby in the womb is indeed your patient. That little baby's life depends on you.

4. Let them know you'd be happy to connect them with another family raising a child with Down syndrome that can answer their questions and give them a window into what life is like raising a child with Down syndrome

When you tell a parent that their little child has a chromosomal abnormality they are going to be scared. They will more than likely cry. That's ok, it's a normal thing to do. They are mourning the loss of the imaginary child they made up in their mind, the child that didn't have Down syndrome. As they mourn the loss of that imaginary child, they will also begin to construct a new child, their child with Down syndrome.

People are scared of the unknown, and Down syndrome will likely be an unknown for a lot of your patients receiving the diagnosis.

One of the best ways to help new parents learn about Down syndrome isn't by giving them an outdated pamphlet, and telling them to go home and "think about it." It's by introducing them to another family who has a child with Down syndrome and allowing them to see what it's like raising a child with Down syndrome, first hand. Tell them it may help them to see that raising a child with Down syndrome is not as scary as they may think.

If you don't know any parents who have a child with Down syndrome in your area, I recommend approaching the nearest support organization for Down syndrome, which will be happy to arrange a contact for you.

Five Ways to Properly Deliver a Down Syndrome Diagnosis

5. Don't suggest that the parents "terminate the pregnancy" because the child has Down syndrome

I can't tell you how many times I've been told by another parent of a child with Down syndrome that their Doctor continually suggested (to the point that they felt pressured) that they "terminate their pregnancy."

As I've already mentioned, as a Doctor you have a tremendous amount of influence with your patients, and they are looking to you with trust for guidance, hope, and encouragement. I'm sure we can agree on the fact that selectively aborting a child based solely on the fact that they have three copies of their 21st chromosome as opposed to two is wrong. So please don't plant the seed of abortion in your patients mind simply because there's a chance their child is going to be born with Down syndrome. Instead, plant seeds of hope, encouragement… and life.

"The future of Down syndrome is in your hands!"

Parents like me love our children, and honesty wouldn't change one chromosome on them.

As an OB/GYN I believe you also love life, and no matter how many times you deliver a baby, or hear a child's heart beat on a sonogram you never get over the wonder of new life. I hope this letter helps you to have that same sense of wonder for all new life, no matter how many chromosomes that tiny little life has.

Parents never forget the birth of their children. I hope that your patients remember you and know that you value all human life. That you love their child. That you love them. And that true love doesn't count chromosomes. It sees beauty in all life.

Babies like my son are counting on you to save their lives from the most dangerous place in the world for a child with Down syndrome, their own mother's womb.

Best regards,
Rick Smith, Noah's very proud father

Source: NOAH'S DAD, 2013.









Mirek

Míra – The Magical Telephone

Our story is about how the magical telephone rang. My husband and I were foster parents for temporary placements, which means we took care of children who were not fortunate enough to grow up with their own family. The placement lasts until their situation is resolved, and afterwards they may return to their biological family, get adopted by a new family, or enter long-term foster care. After 13 months of caring for a little girl who got adopted by a wonderful family, we were waiting for the phone call telling us what little one would need our help next. After a few calls from social services that did not pan out, I couldn't wait at home any longer. I threw a few things into a backpack, called my husband at work, and told him I was going to spend a few days with my parents. Maybe working in their garden would take my mind off things for once. After the hour-long trip to my parents', I changed into work clothes, grabbed a rake, and put my phone on emergency mode by the shed. No one was going to call, anyway. About twenty minutes later the phone rang. It was social services. I tensed and then picked up. The social worker told me, "I have a two-week-old baby boy for you, but think about whether you can handle it, because he's disabled (Down syndrome) and has other health complications. He'll probably spend a year with you in temporary foster care and won't find an adoptive family, so he'll have to go to an institution anyway. I'll call you in ten minutes to see what you decide." I stopped her right away and said she didn't need to call back, because I knew my answer. We would come to get him. I felt it in my bones. I wasn't afraid and I knew we could handle it. And who knows, maybe in a year someone would take him. I wasn't going to take that chance away from him. I called my husband to tell him about it and I let my parents know too. I would have coffee with them and leave again. We had lots to do to get ready (clothes, a stroller, a carseat, a crib, a changing table, and plenty more). I was excited and thinking about how it would be. I didn't have many details.

Later I got the information about when and where to come

Míra – The Magical Telephone

get the baby. My husband and I packed up the baby things and carseat and went to the hospital, where they told us that the baby's jaundice had gotten worse, so they would be keeping him a few more days. They informed us of his medical condition and let us go and see him. We saw a squishy little baby with eyes shut and striped pajamas, fast asleep, helpless. We agreed we would be there for at least two feedings and that I would come alone the next day to be with him. My husband needed to go back to work. The nurse handed me the baby and a tiny bottle. He opened his eyes to look who was feeding him, and the nurse said I was the first person he'd looked at like that. A few days later we brought him home. He was just a tiny thing and had a lot on his plate, but he's a fighter. Today he is a 3-year-old with a sunny disposition and a smile on his lips. He makes progress slowly, but he takes joy in each step and so do we. If you know anything about children with Down syndrome, then you know it isn't a disability. It's a gift. These children deserve to grow up with a family, not in an institution. It upsets me that there are still people today who look at them with distrust. Life with them takes on new values, new priorities. We see much more intensely now what is really important.

In the beginning of our journey as temporary placement foster parents, I listened to different stories and told myself that no child would ever leave our care to go to an institution. I hoped the issue would never come up. I thought everybody would do everything they could in the child's best interest.

When Míra was 8 months old, decisions had to be made about what to do with him, since they hadn't found a family to adopt him. My husband and children and I decided we would not abandon him. When I imagined packing up his things and dropping him off at some faceless institution, waving goodbye and leaving him at the mercy of people who would take care of him in shifts and not care about how he was developing or what would happen to him... Nobody would know what he liked or why he was crying... Betrayed by the only people he knew... I could never forgive myself for that. I know he would have been in institutional care for the rest of his life. We had a number of talks at home about what it would mean and how it was a lifelong decision. Our children stood behind us completely. We'll all do our best to help him be as independent as possible and live the full life he deserves.

I think it was the best decision we've ever made. Míra brings us so much joy. His big and little steps forward make our days richer. We focus more on important things and let the small things go. We've lost some friends, but we also gained many more friends who also have children with Down syndrome. Our lives are richer and offer more opportunities than before.



The sad thing is that we later learned that there are foster parents who would take care of children with Down syndrome. There are adoptive parents who would take them too. And yet these children still end up in institutions if their biological parents can't or won't take care of them. I know plenty of amazing people who have decided to give love and a home of their own to children who would otherwise have grown up in children's homes.

It is important that, when a family decides that it cannot provide a child with Down syndrome with the proper care, the doctors and social workers involved inform the family of the option of foster care. Institutional care should be a last resort. Children with Down syndrome who grow up in a family are able to engage in society and do not need to be put in an institution. They can learn to read, write, and do math. They can be educated. They can go to regular schools. They can learn lots of things, it just takes more effort. Some learn to ride horses and do paravaulting (gymnastics on an unsaddled horse), others enjoy cycling or skiing. They deserve to spend their childhood in a family. Every child deserves to grow up in a family!

How does parents' acceptance influence a child? How does the child then accept themself?

Talking with Jaroslav Šturma, clinical psychologist



Even children with profound disabilities can have acceptance, love and happiness to the degree they are able to experience and their loved ones are able to provide. And even an unusually gifted individual can feel unhappy if they are not loved or if the love they get is conditional: first be this and that, do this and that, and then I will love you. **This is where quality of life is decided.** I know from my own experience that children with profound disabilities have a good life if they are loved, while children without apparent disabilities suffer if they are not loved. Of course when disabilities are involved it can be more difficult for the child to meet the typical expectations of perfection. Children with disabilities put their parents to a sort of test.

This unconditional acceptance is mainly a matter of the very earliest childhood, perhaps the first year. If a child experiences that kind of unconditional love, they see the world around them through the people who surround them, as a place where they are safe and happy and always have someone to turn to if they are in trouble or in need.

We can say that about two thirds of the children we diagnose form **a secure attachment** with their primary caregiver, most often their mother. **Secure attachment is the sense that "I am unconditionally loved". That gives an incredible start in life**, a foundation of resilience to resist disappointment and demands later in life.

About one third of children do not experience this kind of attachment. They may have a relationship, but it is burdened with some form of neurotic tension, such as anxiety, and that is much more complicated. Of course, children with disabilities have a more difficult and complicated time developing secure attachment in their early childhood, when their parents are still adjusting to the fact of their disability. These people need more help, more assistance, more support. That is one of the reasons for early intervention. It should involve working with parents to find ways to support their child's development in different areas as well as the first and most important task of early intervention: helping parents accept their disabled child as much as possible so the child feels unconditionally loved.

So that means supporting the caregivers so they can keep caregiving…

And also ensuring that caregivers don't fixate on meeting some benchmarks they read somewhere about what a baby should be doing at four months, six months, eight months... Especially when disabilities are involved, it is so important to learn to see what the child is doing and how they feel. To focus on the child being happy. And if the child is happy, they mirror that back to their parents, who then rightly feel that they are doing their job well.



Klárka

Klárka

When Klárka was born and the doctors told us the diagnosis that we had no idea about in advance – Down syndrome – I experienced a number of emotions in rapid succession.

First: I don't want this baby, give me another one! Immediately followed by: What sort of terrible mother are you to even think such a thing? Next: We are bad parents because we gave our child an extra chromosome that will make her whole life more complicated. Right after that: It's a challenge, and I love challenges! She'll struggle with some things – but maybe she'll be great at other things! I wonder what she'll achieve even with the cards she was dealt!

Do any of those things seem silly to you? I'm sure they do. They're all silly, in fact. After the first week I settled on the least horrible one, the last one, but I was still pretty "off base". I thought I would be fighting, trying, doing the absolute maximum to teach Klárka as much as humanly possible. But I had forgotten one minor variable in the equation: Klárka herself. The only variable that really mattered. She had her own ideas, plans, and a determination to do some things and not do other things.

It took me a few years to realize that Klárka is not my project. Whether we work hard every day to get close to what her typically developing peers can do, or whether I do my best to develop the natural talents in her is not entirely up to me. It's her choice too. And my job is to support her in it.

As it happens, Klárka loves the same things I do: theater, dancing and music. That was a bit of a relief, because if I had to support her in, say, football, I might have a harder time with it. Even so, it's not always easy, because she wants to do things her own way. Basically, she's always reminding me that "she is not my project".

The roles are kind of reversing – my original plan of teaching her all the things ended up with her teaching me a lot of things too. For instance:

1. The art of living in the here and now and drawing happiness from the simple presence of other people.
(Sometimes Klárka just sits there and excitedly names all the people sitting with us at the table.)



2. The determination to do a certain thing and to find a way to make it happen.
(She always finds a way. She wants a piece of cake? She finds a plate, grabs the biggest knife in the kitchen, and starts cutting the cake. Mug too high up? No problem, she'll climb up there. Yep, it can be a bit of a challenge sometimes...).

3. Tidiness.
(Do you know how we can tell that Klárka broke a mug? We find the shards in the trash... Klárka always tidies up after herself. She knows exactly where everything belongs. She doesn't walk around the house for an hour each morning in her pajamas like the rest of the family. She gets dressed. She makes her bed. She loves mopping the floor.)

4. Patience.
(Yes, some things are more challenging for her, but she has the patience to keep going until she manages them. And so she peels potatoes and carrots while her older brother claims he "doesn't know how.")

5. A sense of fashion.
(Klárka is her own person. Some days she changes outfits multiple times. She comes up with combinations you might think would never go together, but she always pulls them off.)

6. An exceptional talent for dance.
(At a year and a half Klárka could watch Swan Lake. Now that ballet is a part of her life. She puts it on in her room and spends an hour and a half busy dancing. I've had years of dance training myself, but I look at the movements of her hands and the way she emotes and I think to myself: No, I never knew how to do that!)

7. Comedic talent.
(Sensitivity. Empathy. And many more things that she puts to use in life and on the stage. She has performed in a show at Divadlo Aldente.)

In short, Klárka is every bit as much of a personality as each of our four children. Like with the others, we just watch and get ready to support her or redirect her if she aims wrong. But the decision is hers. Just like with our other children, we hope that she will find something fulfilling in her life, work she enjoys, romantic or platonic relationships, her own home, and her own place in society.

What sets children with Down syndrome apart?

Talking with Jaroslav Šturma, clinical psychologist



You can't lump everyone in together, because each child is an individual. However, we can observe certain types or groups.

Some children have trouble with speech development and benefit from early speech therapy and alternate (nonverbal) forms of communication, such as AAC (Augmentative and Alternative Communication) and gestures (sign language), which can be extremely helpful for these children. Sometimes they can struggle with speed and precision in their motor skills, which can make things like learning to write a challenge. In the preschool years it is a good idea to spend a lot of time on fine motor skills through drawing and other practical skills.

The positive side of these children is their warmth, open-heartedness and genuine pleasure in communicating.

The down side is that people with Down syndrome are trusting, sometimes too much so, and may struggle to identify danger. They need a bit more protection from adults even once they are older. They can be naive and easily suggestible. Someone trying to cheat or steal from them would have an easier time than with a person who did not have Down syndrome. It is important to teach them to distinguish between when to give that natural trust right away and when to hold back somewhat.

Another frequent characteristic of children with Down syndrome is a delay in overall intellectual abilities. In some ways they may act younger than their age. Schools usually integrate them into regular classrooms, which is a good and natural thing to do. From an educational integration standpoint, children with Down syndrome and wheelchair users are the easiest groups to work with because they are social and sociable, they like being with other people, and they bring enrichment and sunshine into the class as a whole.

They have difficulty making generalizations and doing what we consider abstract thinking. We have to teach them how to act in certain situations, like only crossing the street when the light is green. From a young age, we who do not have Trisomy 21 learn to make generalizations from the rules we have learned and cases we have encountered. Whether it's little and furry or big with a long tail, it's still a dog. Children with Down syndrome have more difficulty with this. We might have to let them go multiple times through the same situation that they can handle in the form they have learned, but cannot infer the rule and apply it to another, similar situation. For instance, if they cross at the same traffic light every day on the way to school and always see the same lights, they learn to cross the road correctly. However, that does not mean they will be able to apply that experience to a different traffic light in a different spot. We have to help them by practicing. Children with Down syndrome need more repetition and more patience in this respect. As a result, they often take longer to learn.

Photo source: SULOVSKÁ, 2018.



What do children with Down children need from the world around them?

Talking with Jaroslav Šturma, clinical psychologist

Calling for everybody on earth to show each other unconditional love would be a beautiful ideal, a beautiful world, but that isn't possible. What we can ask of the world and all the people in it is tolerance. To accept the fact that we are all different and some of us, including people with Down syndrome, are different in particular ways. While they are a minority, they should never be the targets of bullying or abuse. We should all learn and teach each other that it's important to approach others as individuals. And that some people, including people with Down syndrome at times, need extra support and understanding in certain situations. When someone with Down syndrome encounters a new, unexpected situation and has no friends or loved ones with them, then a stranger (even one who does not feel unconditional love for this person) can still respond calmly and without taking offense that the person does not know how to handle the situation and can help or find someone else to help.



Marek

The importance of being Marek

I pick Marek up from preschool and he runs to me from across the room and jumps into my arms. I love it. He always greets me like this, even if I've just been gone an hour, even if I come and he's the last kid to get picked up, even if he then begs to stay longer. His joy at seeing me is incredible. Another dad next to me comments, "Now that's a greeting!" and gestures toward his son, who is standing in the door and negotiating for more time at preschool or anything else, but hasn't even said "hi" to his dad yet.

That's the most fundamental thing that's different about Marek other than the extra chromosome. He's extra full of love. Even as a baby he was amazing, slept a lot, entertained himself, didn't demand attention, but enjoyed it when he got it. I could work, exercise, and meet up with friends. He started preschool at 2 ½ and did great right off the bat, staying all day the very second day. His teachers love him and so do the other kids. Sometimes I'm taking Marek to or from school and one of the kids from school points him out: "Mom, that's Marek!" It's such a good feeling, like I'm walking with a little celebrity.

Then I think about the people, doctors, and organizations who feel children like mine, children with Down syndrome, shouldn't be born, that they're a burden on their families and on society. And I feel like crying. How could someone think they have a right to decide the fate of another person? Marek was born after a smooth pregnancy. A month before giving birth I was still going out running. I worked up to the day before. Marek was born one month early, but fully ready for life. He wanted to live and I'm happy to have him. He's never done a thing to make it even cross my mind that I'd be better off without him. And a burden on society? I can't count the number of smiles he's gotten



in return for his smile when we're walking down the street or in the store. He just smiles and people smile back at him. He smiles at everybody without distinction: old ladies, young girls, boys, middle-aged men, everybody. I'd like to see the people who think children with Down syndrome are a burden on society, how many smiles do they get from complete strangers.

When Marek was 3, his little brother Albert was born. Marek welcomed him with so much love, even though at the time he was mentally at the age of about 2 and you might expect him to get jealous of the new baby. That never happened. He always wanted to hold the baby, help change his diaper, and take care of him. Today he greets his brother even before greeting me. His Bertie, his little brother. I watch them together, playing, goofing off and laughing, and I feel struck with how lucky I am.

Of course I don't know what's going to happen to us in the future. We had a bit of a rough time with potty training, which took almost a year. But we made it through and I believe we can make it through anything! When I was



expecting Marek, I wished for a little boy with blue eyes who would love me more than anything. And that's exactly what I got. I couldn't ask for anything more. I'm happy when he's happy, and I'm excited to see what progress he makes in the future. I believe in Marek and his future independence. I believe he'll take care of me when I'm old. Maybe I'm naive, but so far everything has worked out, so why not have faith.

How can we come to terms with the fact that our child is different?

Talking with Jaroslav Šturma, clinical psychologist

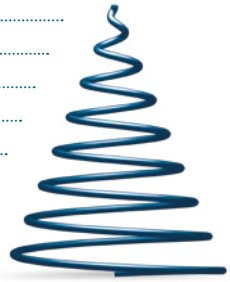
Can you describe, on a general psychological level, the feelings parents often experience when they are given a disability diagnosis for their child?

Yes. This **process of coming to terms** with a child's disability has many things in common with how we come to terms with our own severe or even incurable health condition. This is because we see our children as part of ourselves, part of our own personality. Of course our expectations and hopes are connected with whether our baby is born healthy.

When the baby turns out to have a disability, that shakes us up. There is no set timeline for the process. For some people it takes place fairly quickly, while others may take a matter of years or even their whole lives. We can think of it like climbing a mountain, a journey that first goes through a dark valley, something like the valley of the shadow of death, and when we get through it we can see the light, hope, on the other side. We go from the dark, thick foliage to the sunlight on the mountain. Attempts to depict this process look like **a corkscrew or spiral moving** higher and higher.

The spiral – how the mind moves

8. Solidarity
7. Activity
6. Acceptance
5. Depression
4. Negotiation
3. Hostility
2. Certainty
1. Uncertainty



In any case, we can divide the process of coming to terms with a diagnosis into **three basic stages**.

We can call **the first stage shock**, when we first find out what has happened. At that point it is important to pay attention and take in what happened, just like when we're in shock after a car accident. At first we act on instinct, automatically, in order to survive. Our initial actions do not fit into our life as a whole, though. We don't know which way is up. It is important to make our way through this initial phase, to feel it all and get through to **seeing reality**. Only once we face the truth (that yes, this is how it is, it's not a mistake, the baby wasn't switched at birth, it's not a misdiagnosis) does the now recognized and identified wound come around and start to hurt.

Next is **the second stage**, when our emotions, feelings and **defensive mechanisms** come into play. The very existence of the disability is so at odds with our view of ourselves, our perspective and prospects in life, that we often struggle with it.

Depending on our personality, this confrontation might appear primarily as an attack. We become hostile and mobilize our strength. We want to overcome it with force, whatever it takes. These aggressive impulses encourage us

to look for someone to blame. Sometimes the person we find is the one who gave us the bad news in the first place. When the doctor has to tell parents, "Your child's development is significantly delayed," their initial emotional reaction is often aimed at the doctor. "How can you say such a thing? What makes you say that?" The aggression can also turn inward as a parent blames themself: "How could I… I shouldn't have had any wine at that wedding when I was pregnant…" Sometimes the accusations turn against the other parent, putting a great strain on the relationship: "They said the gene came from you. If it weren't for you, our baby would be healthy…" This is also a huge test for the relationship.

The other basic type of reaction is trying to run away from it all. This might look like giving up, falling into a depression, not being able to see a path forward, losing hope… When that happens, you don't even do the things you could do. One example of running away from the problem, even if subconsciously, is stonewalling and refusing to think about it. In extreme cases parents might even bring in recordings of their baby's babbling and claim to hear comprehensible speech, even though in reality it is wishful thinking so they don't have to confront the fact that something is not right with their child.

The two most **basic responses** to a threat, which a child's disability essentially is, are thus **fight or flight**. The first stage ends with facing the truth, while the second ends with the defensive mechanisms and **strong emotions essentially running out**.

In the third stage, all that energy and mobilized strength that was going to waste suddenly **begins to serve some higher purpose**. Now they start to see some meaning in what has happened to them. They realize that nothing happens without some meaning behind it, and that even this situation can help them gain experience and grow. If they can manage this, they become an incredible source of help and encouragement for others, including for medical professionals and therapists and others who work with parents whose children are disabled. Because unlike professionals who see things from the outside but never experienced it ourselves, they have real life experience. When they talk about what it was like for them or how they approached something, it has **the ring of personal experience**.

This is where parents reach the point of accepting what they cannot change. This acceptance is not some sort of passive resignation, but an active approach to life even in unexpected circumstances. The energy they previously directed toward fighting, seeking out meaningful and meaningless therapies, traveling to see experts even in other countries, etc., can now be directed in a more creative and sensible way. Now they can stop focusing their energy on themselves and rise above their own struggles and their own mountain to see the horizon where more land and more peaks await. Suddenly they can see other people again and how everybody has their own burden to bear and their own suffering to endure. And their experience lets them help others in similar circumstances. **They learn solidarity.** They start thinking differently: they do not just consider how to find the best solution for their particular case, but learn to see that they are in the same boat with many other people affected in similar or different ways, and that they can support and learn from each other.

Their experience makes them the salt of the earth. They enrich the people around them. In reality, if they had not had this experience, they would probably never have achieved the personal growth they did. Of course we cannot wish pain and misfortune on people just so they can go through the fire and come out on the other side with greater maturity. When life turns out that way, however, our task is then to act as humble guides, helping people through the spiral of pain and leading them toward the light.

Suffering in our society is connected to the fact that we are all human, just as we are. We are not immortal or immune to disability or disease. Those things are part of being human. We need to avoid running from them. We need to look them in the eye and face them head-on so we can take these moments and circumstances as an opportunity to live life to the fullest.



Kryštof

Kryštof – with heart in hand

Our son Kryštof is the youngest of four. Our older children were carefully planned, but conceiving Kryštof was one big surprise, accident, chance, or maybe even fate...?

When I first saw those two lines on the pregnancy test I cried, because I felt like I had a lot on my plate already with three boys at home. Terminating the pregnancy was not acceptable to me for ethical reasons, so I took it into my head that this baby would finally be the little girl I always wanted! And so the not-so-pleasant surprise eased into a lovely pregnancy full of excitement for our new baby. Everything went smoothly. The genetic tests came out, to quote the doctor, exactly by the book. The baby wasn't doing as well as expected in the last few weeks, so they moved the delivery date up by a month. I gave birth on November 30, 2009, and when the baby came out as another boy instead of a girl, we were delighted to have a new baby boy.

Kryštof had to be in the incubator at first, and the nurses brought him to me only for breastfeeding. I had a hard time breastfeeding him, and I still remember looking into his slightly slanted eyes and saying to him, "If I didn't know all the tests came back fine, I'd think you must be a Down baby..." Six weeks later, my hunch was confirmed when we got a report back from Gennet that our son has Trisomy 21.

The weeks and months that followed are hard to look back on. I still regret all the days I wasted, unable to look at my baby without seeing his diagnosis before anything else, instead of seeing him as our little baby born out of love. At that time, drowning in self-pity and fear of the future (his and ours), my husband was my greatest supporter. I am incredibly grateful to him for the unquestioning way he accepted our baby, how understanding he was of my initial moods and doubts, and how he always managed to



get me out of my head and back in reality. If I had known half of what I know now, I could have spared myself a lot of worry. But that's how it works, that's the road you have to travel, with all its bumps and falls and getting up again and refusing to give up. It's the experience you pick up and the people you meet along the way.

Speaking of people you meet along the way, I don't want to jinx anything, but I have to say we've been incredibly fortunate in the people we've met so far. When Kryštof was about 4 months old, we started going to regular meetups in Prague for families and children with Down syndrome. I was apprehensive before the first meetup (what if all I meet is other despairing parents like me?), but in the end it gave me a lot of encouragement and hope for the future. Time after time I went home with solid advice, inspiration and motivation to keep me going. Especially the opportunity to share worries and experience with others in the same boat proved to be a lifeline for me. And it still is.

I love reminiscing about Kryštof's four years at preschool. He was super lucky to get teachers who gave the children plenty of space, believed in their potential, and helped them develop that potential with enthusiasm, love, and so much understanding for their differences. Nothing was impossible there, and Kryštof was really happy.

After preschool came elementary school, where Kryštof's luck continued. He got into a private elementary school in Jablonec nad Nisou where we live, into a classroom of typically developing children who give Kryštof an example and natural motivation to keep improving his skills. The school is a friendly environment where children are encouraged to accept the differences of others. Kryštof has an individual educational plan, but whenever possible he works with the other children so he can feel like part of the group. At the moment Kryštof is in fourth grade. His assistant is a key person in his life who has been with him since first grade. They get along very well together and it brings me joy to see and know that it is working well.

Today Kryštof is 11. If I had to describe our lives together, the first thing that comes to mind is definitely love. He is an amazingly empathetic boy who wears his heart on his sleeve and always has a hand ready to help. He always knows when someone is having a bad day. He doesn't like emotional tension and always tries to smooth things over. The path we are walking together is not always easy, but I think our whole family would agree that it has given us more than it has taken. Speaking for myself, I know that Kryštof has given me the opportunity to learn much greater patience and humility than I had before. I have learned to slow down, to worry less about the far future and live more for today, for the here and now, to deal with obstacles as they come and not freak out about things that are miles away. Kryštof has shown us the depth of our characters, and for that he deserves our gratitude.

How can parents prepare siblings for the birth of a baby with Down syndrome?

Talking with Jaroslav Šturma, clinical psychologist



I believe that children usually have a tendency to accept others the way they are. It's adults who have prejudices and preconceptions about people. We put children with Down syndrome in little boxes labeled with the things we think we know about them.

For a big brother who's about to have a little sister with Down syndrome, she's just going to be a little sister like any other. Or a little brother, and at first it's not going to be about whether they are going to play football together or not. It's going to be about learning to accept the baby and respond to him and his needs as they are. In time, of course, big brother will realize that the neighbor kid can play football already and he's the same age as the sibling with Down syndrome, who can't play yet. But that's just learning about life and experience.

The main concern for typically developing siblings of children with Down syndrome is that their parents will focus too much on the child with greater needs. We see two types of siblings.

The first type are those who are subjectively suffering and paying the price. Their parents don't let them be children and make them helpers and caregivers too early. Other children are out kicking around a ball, but they have to stay home and babysit their disabled sibling. When the needs of the typically developing siblings are not respected, it is often more difficult to build a positive relationship between the siblings themselves.

The second type is where the typically developing siblings have time for themselves and their interests, and their parents make time for them as well. In those cases, having a disabled sibling can be beneficial to their lives. They have the opportunity to develop more tolerance and learn to help and understand others. They are often more mature and socially responsible than their peers.

Those are two noticeable groups, but of course many children exist in between the two extremes and do not stand out from their peers in any way.

The same concept applies to parents and siblings alike. Life with a child or sibling with a disability is a rare test. It can lead to good things, growth a person would otherwise not have achieved, but it can also become a source of suffering.



Bejulka

My sister Bejulka



My best friend, my funniest buddy, the most perceptive creature there is, but sometimes also the most stubborn little troublemaker who really gives you the opportunity to practice patience. That's our Bernadeta. How much did this clever, beautiful little girl change my life?

Quite a bit, but I wouldn't change it for the world.

She was born when I was 13, and there are three other siblings between us, so I was never just her sister. I was her assistant, coach, teacher, and plenty of people thought I was her mom too.

Every day is a surprise with Bernadeta, whether she's coming up with a new joke, learning a new piece on her recorder or something new in school, or simply coming up to us and showing off some incredible dance moves during our family music night.

Bernadeta inspired me in my choice of occupation and showed me what really matters in life and that we all have things to learn from each other. She is perfect exactly as she is.



Maruška

Maruška – Love (salt) over gold

Maruška was born in March 2018 as our third daughter (her sisters chose her name – from our pre-approved list – based on the movie Salt Over Gold). She was our only childbirth to go smoothly with no complications, and since I hadn't had any genetic testing during pregnancy, I knew there was a chance she would not be entirely healthy. So my husband and I were not particularly surprised when the obstetrician came to tell us that our baby had some characteristics that "typical" children do not have. The staff at U Apolináře Hospital was very kind, with one exception, so my husband and I celebrated our beautiful Maruška, who wanted to come into the world a bit more special than other babies to help us grow.

Soon she had a heart examination, which did not find anything wrong, thank God. After about ten days (after we both spent a few days in Motol Hospital with jaundice) they confirmed Down syndrome. Her reception within the family was not entirely unconditional, but that soon changed... at first it was mostly one big unknown.

Her big sisters, however, accepted her enthusiastically and love her directness, her sense of humor, and her kisses. They still don't know that she's "different." They love her as she is, encourage her as she makes progress, and they still say she's the most beautiful and funny baby in the world. When it comes to kisses and other signs of affection she truly has no rival.

Fortunately, Maruška has none of the conditions commonly associated with Down syndrome, so care for her is essentially the same as for any other child. Her development simply goes more slowly and we have more





medical examinations than typical. She started walking at 2 1/4 years old and at 3 is still not talking much, but we communicate pretty well with sign language. She gave us some trouble with her hearing exam, but after several attempts it showed that her hearing is excellent. We are particularly grateful for that, because music fills our home and Maruška loves it as much as the rest of us do. She loves dancing and playing the piano. Of course more difficult times are coming, and we know she will need more of our attention and care, but we consider it a challenge and look forward to the adventures we are sure to have together.

I often say that Maruška is our bonus child. She's a bonus that shows us what unconditional love is and what is really important in life.

Trizomie21

Trizomie 21

We Love Being Here

The beauty of life with people who have Trisomy 21 (Down Syndrome)

– Publication not just for parents –

Part 2



Why is breastfeeding important for babies with Down syndrome?

Communication is one of our strongest needs as humans. It plays an important role in developing personality, getting an education, engaging in society and living an independent life. Limitations in speech and communication lead to social isolation and emotional deprivation.

The method of feeding has a critical impact on speech development, since breastfeeding develops and strengthens the muscles in the oral cavity and tongue and teaches them to work together. This creates the basis for the muscles the child will later use to articulate speech.

Children with Down syndrome often struggle in this area, although these difficulties can be alleviated or eliminated with the right care and effort from parents and help from experts. Breastfeeding babies with Down syndrome can sometimes be complicated, so it's best to consult with experts during pregnancy or as soon as possible after childbirth.

Is it possible to breastfeed a baby with Down syndrome?

Renáta Kosíková

Yes, it is. Babies with Down syndrome can even be exclusively breastfed. Every breastfeeding session deepens a mother's love for her baby. Breastfeeding is a natural biological process. The best advice a doctor can give you is to take your baby home and shower them with all the love, warmth, safety, and attention your family can give. That's what will most help your baby to achieve their full potential. Most children with Down syndrome are happy, playful, and a delight for the entire family. Your baby will learn more and faster in a happy, stress-free environment, and breastfeeding helps create that environment. Your encouragement and smiles will come back to you as encouragement and smiles from your baby.

Can a baby with Down syndrome be strong enough to learn to breastfeed?

Yes, although sometimes it takes a little longer for the baby to learn to suck correctly. Even an experienced breastfeeding mother may need a little more time and a few tricks up her sleeve to help her baby with Down syndrome latch on and breastfeed. If you have any questions or concerns about breastfeeding at all, you can call an experienced lactation consultant who will be happy to give you all the support you need.

Breastfeeding strengthens the mother/baby dyad and is also the primary factor contributing to the baby's nutritional wellbeing. The advantages of breastfeeding are even more pronounced for babies with Down syndrome. They are more susceptible to infection than other babies, so the immune factors in colostrum and breastmilk are particularly valuable to them. Recent research has shown that breastmilk contains lactoferrin and transferrin, which prevent the growth of harmful bacteria in the digestive tract. Bifidus factors in breastmilk actually support the beneficial bacteria that are essential for gut health. Another layer of protection comes from lysosomes, which attack and destroy bacteria. Breastmilk also contains antiviral factors. These are just a few examples of the ways breastmilk benefits babies. High levels of taurine (an amino acid) and lactose are also of interest here. These two nutrients have been found to be essential for early childhood growth and especially brain development.

Many pediatricians tell mothers that the most important thing for babies with Down syndrome is to gain weight based on the standard growth charts, and if they breastfeed, that's nice, but that's about it. However, research shows that **breastfeeding is irreplaceable**! It is an excellent **food for their undeveloped digestive systems and helps them develop strong tongue movement and jaw development**.

When a baby is born with Down syndrome, parents often have many different concerns and fears. The baby may be difficult to rouse and have a weak sucking reflex. Some babies may have respiratory or other, more serious troubles. If your baby is weak (hypotonic) after birth, they may have some difficulty learning to suck and swallow, so you will need to stay calm and patient.

Babies with Down syndrome are more prone to respiratory infections and digestive problems. Breastfeeding reduces the occurrence of both of these problems and most likely reduces the severity when they do arise. Babies with Down syndrome are often quiet and sometimes have poor muscle tone (hypotonia) and general weakness after birth. For that reason mothers need to watch the clock and regularly pick up the baby to offer the breast instead of waiting for the

Is it possible to breastfeed a baby with Down syndrome?

baby to cry wanting to be fed. Babies should be encouraged to nurse about every two hours during the day and several times in the night.

A baby who naps in a crib will most likely not rouse to nurse often enough on their own. It is better to nurse every hour a little at a time than to have a single insufficient nursing session every three hours. Newborns find nursing quite tiring at first, so longer breaks between nursing may lead to insufficient nipple stimulation. In order to encourage sufficient lactation, it is best to breastfeed as often as possible, especially if your baby with Down syndrome has a weak sucking reflex or tends to fall asleep a lot.

Sometimes babies keep their tongues stuck to the roof of their mouths. If this happens, you can put your pinky between your baby's tongue and the roof of their mouth upside down and then turn it over. To get the baby's sucking reflex to where it should be, this procedure should be repeated four or five times before each breastfeeding session. Put your finger into the front of your baby's mouth and press it slowly into the baby's mouth so they think they are beginning to suck. Some mothers do other orofacial stimulation to encourage better sucking before each breastfeeding session.

Once you come home from the hospital, make sure **to take care of yourself as well**. You need to rest and eat properly just like when you were pregnant. It's a great idea to have someone available to take care of you while you take care of the baby.

Take responsibility for your baby into your own hands and find out how much weight they should be gaining. Watch your baby carefully to see if they are crying for hours in hunger, if they have enough wet diapers and at least some poopy diapers each day. You may find that your baby digests all the milk and does not have any poopy diapers.

Keep in mind that baby girls tend to gain less weight than baby boys. The average minimum weight gain is about 120 g per week at a birth weight of 2.41 kg. Some babies with Down syndrome do not gain weight as well as they should, so doctors often recommend introducing solids earlier than usual. Follow the advice of your pediatrician and lactation consultant. Let your baby's needs be your guide. Many babies with Down syndrome nurse at a slow, unhurried pace, so be prepared for long nursing sessions. You can both enjoy these quiet, peaceful moments together. If you have other children, you can read the older ones a book while nursing the baby.

The rewards from your baby successfully breastfeeding are certainly worth the extra effort, so don't get discouraged if you encounter challenges along the way. Your baby will catch on with your loving assistance. It would be helpful to learn as much as possible about breastfeeding. You can find information and contacts for certified lactation consultants on reputable websites about breastfeeding. Your health insurance may even cover the cost of their services.

New parents often don't know that children with Down syndrome can have nearly typical social and emotional development. Babies with Down syndrome may do better with stimulation, attention, tenderness, and the loving care that all babies need. They will return your love a hundred times over.



Practical tips for breastfeeding babies with Down syndrome

Jana Vundrová

Parenting is a lifelong process in which parents try to raise and protect their child through adulthood and independence. It is a great gift, but also a great responsibility. Medical science allows us to predict the birth of a child with some health limitations even before they have left the safety of the womb.

Parents and family members should learn as much as they can about the disability before the baby has been born. Parents should visit a lactation consultant before the baby is born who will continue to work with them after birth as well. The lactation consultant can explain any possible complications involved in breastfeeding babies with Down syndrome and advise parents on what breastfeeding aids might help make breastfeeding a success as soon as possible after the birth. Parents should be informed that babies with Down syndrome have a weak sucking reflex and muscular hypotonia (low muscle tone). In some cases, full breastfeeding may be achieved only a few days after birth, once released from the hospital.

A breast pump can help support lactation. Mothers can encourage the baby to latch on and feed even though their weak sucking reflex may mean they do not get much milk. At the same time they can use a pump attached with a strap, keeping the mother's hands free to hold her baby while breastfeeding. This saves time as well. One good breast pump strap is available from Medela. Your lactation consultant can advise you on purchasing or renting a particular type of breast pump. You will almost certainly be recommended to get a hospital-grade electric double breast pump in order to get lactation going. Rental stations all around the Czech Republic have these pumps available. DN Formed Medela offers a number of breastfeeding aids that may be useful to parents of a disabled child with a weak sucking reflex. The Calmita nipple and Calma system can be a great help, as they give a very similar experience to natural breastfeeding.



Nipple shields can also be extremely useful in establishing the breastfeeding relationship. Mothers can either use them for the entire time or trim them gradually so the baby learns to drink directly from the breast.

Many mothers feel that pacifiers are detrimental to breastfed babies. This applies to babies in the physiological sucking phase. Your physiotherapist will advise you on whether a pacifier is appropriate for babies with low muscle tone in the facial muscles. A physiotherapist can teach parents the correct methods for orofacial stimulation to improve the baby's breastfeeding results. After the birth of a baby

with Down syndrome, a lactation consultant visit should be permitted while still in the hospital. If the mother makes up a birth plan, it would be a good idea to include this in the notes. It would also be a good idea to visit a physiotherapist before giving birth so they can work with the chosen lactation consultant. You can take a nursing pillow to the hospital with you and then use it at home as well.

Close relatives can be of great assistance for parents, but sometimes they can also make things more difficult. It would be wise to get the extended family together before the baby is born and let the baby's father organize the people offering to help. A father's role should not be underestimated. He may have a natural ability to keep a clear head in a complex situation, which can help with the heightened emotions that understandably arise after childbirth. Lactation is less successful when stress is high. Stress can also block the letdown reflex during breastfeeding or pumping. Based on experience, we recommend that the father take time off work while the mother is still in the hospital as well for about a month afterward. Fathers can also take charge of organizing any help from the extended family in conjunction with the mother's wishes. The time spent putting the baby to the breast, pumping, and doing the exercises assigned by the physiotherapist can be quite mentally draining, so it is important to keep a clear head about the whole situation. Parents may find it helpful to meet with a therapist familiar with the issue. Consultations are available online as well as in person. Parents can take advantage of the financial support available in the healthcare benefits from their health insurance company for the recommended consultations. It is helpful if the professional team (lactation consultant, physiotherapist, psychotherapist) works with the family long-term while the baby is fed using breastmilk.

Parents need to have a team they can trust to help them. Breastfeeding a baby with a disability is difficult at first, but, with good cooperation between the parents and professional team, it is possible.

If the baby's health deteriorates (frequent middle ear infections, heart operations), **direct breastfeeding may not be possible**. You can pump to keep your milk supply, and if possible arrange with the medical staff to have your breastmilk fed to your baby (using the Calmita system or even a feeding tube), administered either by yourself or by a staff member. If you are able to stay in the hospital with your baby, ask the staff if you can pump in the room with your baby. This is important for the immune properties in your milk. If that is not possible, breastmilk pumped elsewhere is still more beneficial than formula. For the rules on milk storage, please see www.kojeni.cz.

If you keep your milk supply going, you can go back to breastfeeding directly when possible. If your baby has trouble latching back on, make sure you get the right support to remind you that you can still feed your breastmilk to your baby in alternate ways if your baby continues to struggle with latching on. If parents don't have the strength to approach the hospital staff, ask your lactation consultant to talk to them for you. This teamwork means you won't have to feel so alone in these difficult circumstances.

Alternative breastfeeding aids: www.medela.cz

Helena was born with a serious heart defect (I went to my ultrasounds, but the doctors did not see her AVSD). Basically, her heart was full of holes and oxygenated blood was mixing with deoxygenated blood.

Despite the best efforts of the neonatal nurses at U Apolináře Hospital, we did not manage to get Helena to breastfeed in the hospital because she was not able to nurse for long enough to get full, even though my milk came in strong. With regular pumping and bottle-feeding using a very soft rubber nipple, we managed to feed Helena pumped breastmilk until she had her heart operation (over three months). It was extremely challenging, pumping every three hours and then feeding on top of that, but I followed the advice of my mother-in-law to keep putting the baby to the breast from time to time, so her sucking reflex did not disappear and we managed to breastfeed normally after her operation. I nursed Helena for another year after that.

Sucking dynamics in babies with Down syndrome

Eva Matejičková



Babies are born with an absolutely natural ability to suck, and nobody really gives it a second thought until a baby repeatedly struggles to open their mouth sufficiently to latch on. Struggling to breastfeed has a negative impact on the rising stress levels in the family, especially when advice from older relatives and friends fails to help. If breastfeeding problems came up at the hospital and the staff was not able to work with the mother to solve the issue, the family has to scramble to find information and assistance on their own.

Problems with the sucking reflex often stem partly from the method of delivery (key movements during the phases of labor, positioning, fetal rotation). Sometimes the birthing process can lead to a blockage in the head and neck joints related to the position of the head, breathing, and movement of the jaw and tongue.

Besides the obvious nutritional implications, why are **problems with infants feeding (sucking) and older children (swallowing)** so important? Sucking is a complex, coordinated process that begins in the fetal phase with practice thumb sucking (around the 4th month of pregnancy). Any deviation from the physiological process of sucking after childbirth represents a medical problem (insufficient nutrition for the baby) as well as a psychological and social problem that **interferes with the first interactions between mother and baby**.

The processes of sucking and swallowing have not been fully studied yet. Sucking from a bottle involves a different mechanism and muscle coordination than feeding directly from the breast (CASTILLO-MORALES, 2006). Swallowing is a complex process that is divided into three stages (oral, pharyngeal, and esophageal) and engages the epiglottis as well.

Inducing physiological sucking and swallowing is **related to the position and activity of the body** (CASTILLO-MORALES, 2006). The orofacial structures (the structures of the head and neck) and the body work together to induce and secure smooth function in the process of sucking, swallowing, creating saliva, making facial gestures, and articulating speech. Swallowing during food intake works in coordination with

Sucking dynamics in babies with Down syndrome

breathing in the most complex interaction of the process: inhale, swallow, exhale. In order to suck properly after being born, babies need sufficient oxygen saturation: **they need to breathe correctly and to breathe enough**.

Breathing is another complicated process influenced by many different factors. It changes with age, exertion, illness, stress, etc. The way newborns breathe changes after the first three months (improved coordination). **Breathing is connected to food intake** and the process of moving from the mouth to the digestive system as well as to **bowel movements**, which are a common problem at the newborn stage and beyond.

The sucking process is influenced to a significant degree by the movements of the baby's arms and legs, sensorimotor sensations with the mother's body, and later even contact with her clothing and the structure of the material, visual and auditory perception, the first "play" associated with the movements of the baby's whole body in response to signals from the mother.



Mothers need to know the best practices for ensuring the best possible development for their babies and toddlers, such as reducing the support area while swaddling, correct placement in the baby bed or stroller, babywearing only in the diagonal position (which supports the baby with no overhang, stretching, or tilting the head), and why some types of carriers are not recommended for babies and toddlers with Down syndrome. Even in the first few days after birth, parents can begin **developing active play in their babies**. The right approach can make it easier to engage your baby in all aspects of their development under natural conditions. Instead of a passive observer rewarding parents with a smile or minimal movement, your baby becomes an active participant in play.

Wearing your baby in a carrier in an upright position with their chin on your chest is not ideal. In that position, your baby's jaw and the tip of their tongue is protruding. Their arms hang passively at their sides, making them difficult to lift against gravity, while their legs are spread wide apart. They have no ability to actively change their position.

It is important to place babies with Down syndrome in the ideal position in the stroller, for instance, so they can actively engage their facial muscles as well as their bodies to interact with their mother, who can respond enthusiastically to their expressions. **Proper breastfeeding technique and well-chosen placement of the baby during the day both help build a strong sucking reflex.**

If the correct steps are taken in therapy and stimulation for the baby based on their neurophysiological conditions and abilities during their development, even highly hypotonic babies can achieve good results that approach the abilities of babies without Down syndrome without much age delay.

In case of difficulties with sucking or overall movement from the infant stage onward, assistance is available **with *Orofacial Regulation Therapy and Neuromotor Development Therapy based on Castillo Morales* in conjunction with *Prima kojení* lactation consultants**.



Mariánka

Mariánka – a gift from God

Mariánka and her brother Albert were born on May 8, 2020 at home, just like her older siblings Julinka (6) and Staník (3 1/2). Now she is 10 months old.

In September 2019 I found out I was pregnant. I had originally intended on only visiting the OB/GYN two or three times during this pregnancy, because I knew that too many checks and tests can do more harm than good to mother and child, whether mental or physical. My plans changed completely, however, after my first visit at 12 weeks where the doctor told me I was having twins. Even though this is my area of expertise (I am a placenta processing specialist, lactation consultant, and doula), I knew very little about twins. I got some medical literature on the topic, connected with other mothers of twins, and started studying.

At the beginning of the second trimester I started feeling frequent flutters during the day. I didn't think much of it, since I had experienced the same in my previous pregnancies, even though it started after week 20, not week 14. Around week 20 I started experiencing some morning sickness. In week 29 I had to be admitted to the hospital because of serious digestive problems. I sought advice from people with more experience, and with God's help and theirs I made it through to my due date.

Mariánka was born first and our birth assistant voiced her suspicion of Trisomy 21 right away. That was a major surprise for us and we transferred to the hospital immediately to have her heart checked. I spent two weeks there with her, since she had to stay in the NICU. I'm afraid that I had a very negative view of her diagnosis the whole

Mariánka – a gift from God

time we were there. I was sad, disappointed, and didn't know what to do. Breastfeeding Mariánka proved difficult, almost impossible while in the NICU. Even as a lactation consultant myself I still felt helpless. They released us from the hospital after removing the feeding tube, and I fed her pumped milk from a bottle and tried getting her to latch on to the breast directly as well.

Once we were home, the situation started to improve. I had another lactation consultant come to visit us, and that helped immensely. A lady from our church also helped me see my little girl as a treasure from God. She reminded me of Mark 9:36-37. "He took a little child whom he placed among them. Taking the child in his arms, he said to them, 'Whoever welcomes one of these little children in my name welcomes me; and whoever welcomes me does not welcome me but the one who sent me.'"

About two weeks later we were able to phase the bottle out completely, and by the time they were six weeks old I was ready to take the twins out into the world. Mariánka gained weight more slowly than Albert, but overall she was thriving well. We visited Dr. Matejičková several times and started attending swim classes for babies. I could see that both were helpful for Mariánka.

Our whole family showers her in love. She is an amazing little girl and we are so happy that God gave her to us.





Early intervention – DOREA Early Intervention Center at the Silesian Diaconate



Early intervention is a social service, also known as a social prevention service. Section 54 of the Czech Social Services Act (Act No. 108/2006) defines early intervention as follows:

1. **Early intervention is a field service that can be supplemented by outpatient service provided to a child and parents of a child under the age of 7 who is disabled or whose development is at risk due to an adverse health condition. The service is focused on supporting the family and promoting the child's development with regard to their specific needs.**

2. **The service described under paragraph 1 includes the following basic activities:**

a) educational, training and activation services,
b) facilitating contact with the social environment,
c) social therapy activities,
d) assistance in exercising rights and legitimate interests, and taking care of personal matters.

Early intervention centers operate all around the Czech Republic. **The Czech Early Intervention Association** serves early intervention providers all over the country. Member organizations undergo an inspection and, once they pass it, they receive a certification guaranteeing the quality of early intervention services and adherence to certain defined standards of service (www.arpcr.cz). Every early intervention center specializes in serving children with a particular type of disability, such as visual impairment, hearing impairment, or autism spectrum disorders. To find the right early intervention center, parents can use this website with a map of centers around the Czech Republic: www.ranapece.vcasnapomocdetem.cz

How does early intervention take place?

What sets early intervention apart from other services is the way it works with the needs of the whole family and responds to the difficult situation the family finds itself in. In other words, early intervention responds to the specific needs of the child and gently works to minimize the negative impact of the disability on the life of the child and of the family as a whole with the goal of securing the child's care in the home environment and avoiding placement in institutional care. In particular, it consists of supporting the child's development, helping the family adapt to and learn to handle their new



life situation, and facilitating the family's incorporation into everyday life (preschool placement, parents' return to work, social services to help the family care for their child, etc.). **Families can contact early intervention immediately after their baby is born.** Early intervention primarily **supports families in their own homes**. This spares families the stress of another trip somewhere, as their visits to experts in various fields (neurology, speech therapy, clinical psychology etc.) tend to be quite frequent. Children also act natural in their home environment, so parents can more easily discuss everything they are struggling with or need advice on. Another advantage for families is the fact that **services are provided free of charge**.

The family's assigned **early intervention specialist** is the key worker who guides them through the process. This specialist accompanies the family through the first years raising their child with extra support needs or disability. They respond on a professional and human level to the needs the family shares and they come with new ideas, compensatory and didactic aids to support the child's development. They recommend appropriate literature or other professional services that the family may find helpful. The early intervention specialist can also lend the family the aids they use to work with the child during the consultation at home as well. Then the family can use the aids as instructed by the specialist between consultation appointments. At the next appointment they can share how the assignment went, what has changed, what needs more work, and any other topics they are dealing with at the moment.

We meet with a very wide range of disabilities in early intervention. Some are mild, sometimes due to premature birth, some are due to rare conditions, and some involve severe physical and/or mental disability. Every child needs an individual approach that believes in their potential. Like with other disabilities, it is not always clear in advance what children with Down syndrome will be able to achieve in their life. Every child should be supported in developing their abilities so they can meet their full potential. In the first few years of life (0-3) a child's brain can compensate and develop new paths and mechanisms even in areas where their development is delayed or significantly disrupted. They say in the early years children are like sponges, soaking up information and absorbing as much as possible. That is why supporting their abilities at this key age is essential.

Children with Down syndrome from the standpoint of an early intervention specialist

Lucie Freibergová

When the doctor diagnoses Down syndrome after a baby is born, parents typically experience a great deal of fear and concern for the future. Many doctors only add to parents' fears by giving negative information about the symptoms of Down syndrome. Often parents meet with suggestions from doctors even before they leave the hospital that they should put their child in a home for disabled children. Parents tend to find this extremely upsetting and it makes them feel even more hopeless and anxious. The first social service parents seek out is usually early intervention. In recent years parents are learning about early intervention and available services quite quickly, thanks to doctors, social media, and interest groups for parents of children with Down syndrome. This means that a family whose child has Down syndrome can often start working with early intervention when their child is still quite young.

As an early intervention specialist, I see how worried parents are at the first few consultations about how to raise a child with Down syndrome. Many parents see Down syndrome as a stigma and believe that raising their child will be complicated because the child will need a different, more demanding approach to parenting that the parents do not know how to do. Many parents also worry about how other children and society as a whole will accept their child. I always love seeing how all these worries melt away over time as parents realize that a child with Down syndrome is, first and foremost, a child – sweet, playful, curious – and that they do not need any special parenting tricks to raise them. They need consistency, love, and patience, just like with every other child.

Children with Down syndrome are highly social. They love being around other people, adults and children alike, and they often initiate first contact with people around them. Their open and sincere natures tend to make them popular with others. Like other children, they want to explore the world and play. They cooperate and play with adults very well. They are happy for every bit of attention they get from a grown-up. Children with Down syndrome are very skilled imitators. They imitate their siblings while playing and doing other activities. They imitate their parents. This ability lets them learn a variety of skills quite quickly.

Thanks to all these traits and abilities, children with Down syndrome typically do very well in integrated classrooms. A student with Down syndrome in a preschool or elementary school classroom with typically developing peers offers enrichment for everyone involved. The child with Down syndrome gets a suitable education and finds motivation in being with the other children. They learn how to interact with others and become part of a group. Their classmates get the chance to learn tolerance and patience.



As an early intervention specialist, I always look forward to working with families where a child has Down syndrome, because I know that our work together will lead to great progress in the child's development and a major shift for the parents, who over time will lose much of their fear and concern and will start seeing their child as a gift.



Jonáš

Jonáš – it's like he's always been with us

While I was still pregnant, we learned that Jonáš would be born with an extra chromosome, and the period surrounding the genetic testing is not easy to look back on... The only "advantage" of early detection, if you can call it that, was giving us time to get used to the idea that, starting very soon, a lot of things would be quite different. Today, however, we have met so many incredible people thanks to Jonáš, like another family whose little boy has Down syndrome, an early intervention specialist we met through that family... and some who seemed to just fall out of the sky to support us. That is certainly one of the gifts Jonáš brought into our lives before he was even born.

The pregnancy went smoothly from start to finish and Jonáš came into this world right on time. He had his first operation (on his digestive tract) the day after he was born and over the next few years had several more. With God's help he got through them all, and today we look back at that period in our lives and it feels so far away.

Jonáš is our only child at home, but he has two adult brothers. His brothers, their families, and our whole extended family mean that Jonáš knows he is part of a "big family" that he loves.

When he was about 3, we ventured out into the world and started meeting at MŠ Štíbrova (a preschool) with a group of parents whose children have Down syndrome. We slowly started taking in more people outside the family. It gave us a good start – the world was friendly to us. Jonáš attended preschool at MŠ Štíbrova, which gave him an excellent foundation for the future. Among other things, he had his first experiences of independence and adventure at their winter and summer school trips.





Jonáš is currently in second grade at an elementary school in Prague 6 that specializes in students with learning differences. It took him a bit to adjust to the new expectations. At first he mainly watched, which is usually what he does when a major change comes along. As he got used to the new environment, he started showing his full personality. He loves his classmates and teachers. Not a day goes by that he doesn't talk about them.

Our lives with Jonáš are full — full of Jonáš.

He may be developing more slowly than others, but we still feel like he is growing up right in front of our eyes. It is incredible to watch how he is changing. We rejoice in each bit of progress and success along with him.

Jonáš loves family gatherings, eating at the big table, and making music together. He loves laughing, goofing off, joking around, sometimes even showing off... He can be a bit of a troublemaker and boundary tester from time to time, but he also loves to snuggle and cuddle. He has strict ideas about how certain things should be, and he makes sure they stay that way. Of course, he also gives us opportunities as parents to practice patience and other parenting skills. His strong will and a certain level of obstinacy are part of who he is.

But as a whole, Jonáš is mainly about a huge smile, guileless eyes open wide, and warm hugs. We all love the moment he wraps his arms around us and bumps heads with us, because of course we're all the best of friends.

Early intervention – Diakonie ČCE Praha

Veronika Strenková



Early intervention offers parents psychological support and partners with them so they know they are not alone in their difficult circumstances. Specialists advise parents on how to support their child's development and focus on the child's and family's strengths. They give the family a clear overview of the social and legal issues (possible government support and the social security system generally), the preschool and early elementary school system, social services available, and taking care of any additional needs the child may have. Early intervention always takes into account the family's location (accessibility), references, wishes and possibilities.

Early intervention assumes that parents will take an active role in the process. For that reason the parents need to request early intervention services directly – by phone, email or other means. Additional consultations take place by agreement, usually one to two months apart. Each family has a specialist assigned to them so they can consult on whatever they currently need or may consider in the near future.

Children like the specialists because of the big bags they carry with toys and aids the children can play with and boost their development at the same time. Early intervention focuses on keeping processes as natural as possible and always puts the child first. In addition to their professional skills, early intervention specialists should bring families enjoyment, playfulness and a healthy curiosity. That is the best way to get children and parents on board and help them along their path.

Our experience with early intervention

Zuzka Šimonová

When we were looking into early intervention services, we found it a bit off-putting that it was described as social work. That sounded like somebody coming over from child protective services to check up on us, judge us and maybe even "pass our case on" because we weren't doing enough for our son. Looking back, I have to laugh at that impression.

After the very first visit we understood that early intervention is on our side. The same specialist (Helena is amazing) visits us at regular intervals, usually every two or three months. She helps us with whatever we're dealing with at the moment with our son. It might be choosing a speech therapist, getting compensation aids, requesting government support as caregivers, getting ready to start preschool, or any number of other things. One of the biggest advantages of early intervention is that it takes place at home, so we don't have to go anywhere. We stay in our own environment, where we feel most comfortable. Early intervention provides us with invaluable advice and experience from others, but they also lend us toys and learning aids that are often quite expensive and children grow out of them after just a few months. Early intervention is an excellent service that makes an often challenging journey or situation easier to handle. There is no reason at all to fear early intervention or refuse it because of any preconceptions or lack of knowledge about it.



Helenka

Helenka – Our exceptional child

How much did Helenka's birth change our lives? A lot! Helenka is our first child, so we were nervous wrecks already, and we were trying to find a place to live at the same time, so it wasn't ideal. Then, two days after she was born, the head doctor, standing right there in the hallway of the hospital, told me that he suspected Trisomy 21. I was shocked and terrified. My husband and I didn't consider putting Helenka into an institution even for an instant, though – she was our baby! The truth is that when our daughter was born the hospital basically presented it as "The Big Bad Down Syndrome," and that had a quite negative impact on us. We spent a few months feeling sorry for ourselves and grieving, but Helenka needed our care and she was going to have major heart surgery, so we got caught up in the cycle of feeding, changing, examinations and therapies. We just observed the reactions from people around us, sometimes quite crude, and did our best to handle the situation.

I also read a lot of online discussions, shaking my head in disbelief at some of them. Czech legislation doesn't see it the same way as I do, but ever since I was a child I've believed that terminating a pregnancy is killing an innocent child, and I decided to live my life accordingly. I often process things through media, so the film *The Hardest of Choices* by director Dagmar Smržová confirmed my gut feeling.

After spending time grieving, we decided to check out a meet-up of families whose children have Down syndrome, which we found very helpful. The mother-and-child meet-ups organized by the preschool MŠ Štíbrova were ofgreat benefit to me personally. They made me feel like we belong somewhere, like there was finally somewhere that no one was looking at us like we were aliens.

I lost my second pregnancy to a missed miscarriage, and our firstborn daughter was a great comfort to me at that time. I understood that losing a child is much worse than having a disabled child. Then, after my next pregnancy, Helenka became a big sister. It's great, but it really has its ups and downs. Not just because of Helenka, but because of her younger siblings Kristýna and Ondra.

Since we had Helenka, we have seen how she moves forward and how our own values are changing. And we've

had a certain loss of illusions too. To tell you the truth, with three young children running around, you don't have much time to think deeply or feel too sorry for yourself. Caring for a child with a disability is a bit more challenging (I struggle with fatigue and losing my patience). In some respects, though, I feel it's easier to work with Helenka than with her siblings, but it's certainly nothing we can't handle.

Our firstborn daughter expanded our horizons, introduced us to so many different people and personalities, and helped us live through all sorts of situations we wouldn't have experienced with only typically developing children. I am happy that we have Helenka and that we did not give up fighting for our little girl as doctors recommended.

Our Helenka

I was born a little bundle of love. I weighed 2,8 kg. The doctors thought something was up with me, so they did some genetic tests. My daddy came to the hospital to be with my mommy and took time off work right away. Then we had to wait a week for the results. And what did they say? That I had Down syndrome. My mommy and daddy thought I was a beautiful little girl and they call me Helenka.

When my grandpa held me in his arms, he said I was like a little furnace. Believe it or not, I hardly cried at all, because my heart was sick. I was going to have an operation. Everybody tried getting me to eat as much as possible so the scale would show the number that meant I could safely have my heart operation. My parents were delighted to see how I thrived and learned to cry out loud, which they'd never heard before.

Later my little sister Kristýna was born. I used to go over to look at her, sometimes give her a cuddle or cover her up with a blanket. I love being surrounded by chaos, so I like to throw things on the floor and then laugh at how surprised people are at what all can end up on the floor. I don't talk to other kids much, but my little sister cuddles with me in the evenings even without talking. I can say grandma, grandpa, hop, and a bunch of other words of course, but I'm not here to show off. When I'm sitting at the table waiting for lunch and I'm hungry, that's when you'll hear my voice. Sometimes I break down in tears just to let people know my tummy is hungry. I can blow raspberries and then laugh, too, but the grown-ups tell me not to do it... Any idea why? I love playing in the sandbox and going to my school, where I have friends and nice teachers.

I'm always smiling and laughing, and when people turn around to look at me, they have no idea that I was born so that everyone would help each other more and learn to have solidarity and patience. I like living in the world, and my loud peals of laughter prove it.

Aunt Veronika, on behalf of Helenka

My daughter gave birth to Helenka when she was 27 years old. Now Helenka is 8. I live 15 minutes from my daughter's family, so I can go over to help out. My daughter had two other children after Helenka: 5-year-old Kristýna and 3-year-old Ondra.

Helenka doesn't talk much, but she repeats words and expresses herself quite a bit by waving her hands. She loves drawing. She adds rain coming from the clouds, eyes and a mouth for the sun, windows to houses, colors to the wheels of a car, and even tries to put windows on a car in a picture. She likes helping people cook. She wants to roll the dough and put the spoons on the table. It may take her a little longer, but she can get herself dressed and eat on her own.

I used to take all three children to the playground, but Helenka would often run away from me towards the preschool nearby. She doesn't like being bored. If you don't give her something to do, she'll throw things on the floor.

When she says, "Hi, Grandma," I'm happy.

Helenka's grandmother



Congenital heart defect

Jan Machač

A congenital heart defect means a problem with the heart (even combined with other things) that is present at the child's birth. This is one of the most common congenital defects and affects about 1 in 100 babies in the general population and 30–50 % of babies with Down syndrome. Congenital heart defect can cause shortness of breath, fatigue, and exhaustion. It can also affect how well the baby thrives: sometimes it interferes with their ability to feed and slows their growth or development. Sometimes it has no symptoms at all.

The most common type of congenital heart defect is a septal defect, a hole in the septum (wall) between the upper two chambers (atrial septal defect, ASD) or lower two chambers (ventricular septal defect, VSD) of the heart. Both defects allow oxygenated blood from the right side of the heart into the left side, bypassing the lungs and therefore not passing enough oxygen to the body. Both defects are fairly common in children with Down syndrome. However, only about one in three affected children needs a heart operation, and the need to operate without delay is fortunately quite rare.

If a doctor suspects that a baby may have a congenital heart defect (for instance, after hearing a heart murmur through a stethoscope), they send the baby to a pediatric cardiologist for further diagnostic and therapeutic processes (EKG, echocardiogram, blood tests). Sometimes they will consult with a cardiac surgeon to determine whether an operation is necessary. It is naturally very stressful for the parents when a child has to have a heart operation, but surgeons today perform operations of this type with high rates of success.



Liduška

Liduška

Liduška was born in September 2011. We were so excited to meet her, us parents and her four older siblings.

The pregnancy became more difficult, however, when the doctors determined that our little girl had a serious heart defect often associated with Down syndrome, which they also then confirmed with testing... It was a difficult period, but our cardiologist assured us that the heart defect could be corrected with an operation. We did not know anything about the condition at the time, so she was also the first to give us positive information about Down syndrome and how people who had it could still live a meaningful and happy life.

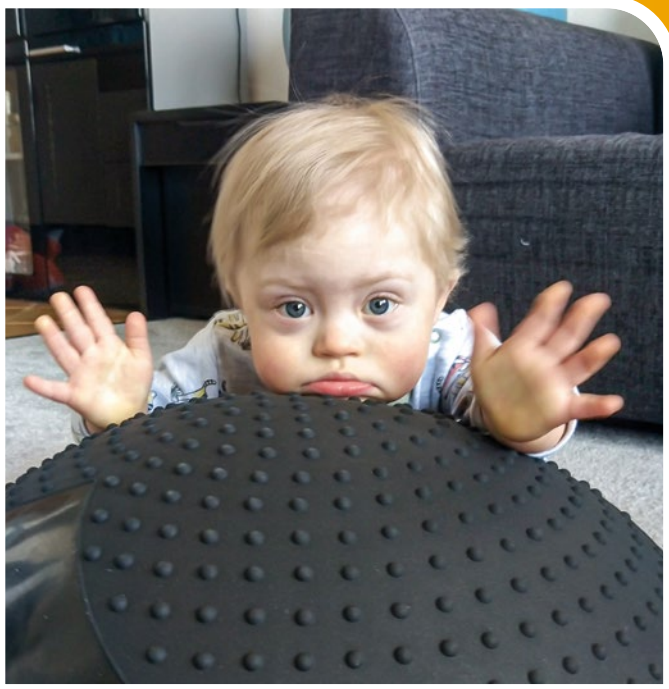
Gradually we began to come to terms with the idea. We were still concerned, however, at what would happen when the baby was born. Our fears disappeared the first time we saw Liduška. She was a beautiful baby. At first glance she didn't look any different than her siblings. We knew we would do everything in our power to help her live a life just like theirs.

Her heart defect did not have any major symptoms after she was born. We just had to be under medical supervision and wait until Liduška weighed at least five kilograms so she could have the operation. She got through it very well. If it weren't for the scar on her chest, we wouldn't even know she ever had an operation.

As far as Down syndrome itself, we don't notice it much either at this point. True, sometimes it takes her a little longer to understand or learn something new. We always get her professional help when we can. Our family loves to travel and Liduška has adapted to it well. We have been taking her with us everywhere since she was a baby. She loves travel too. She even likes spending hours in the car or on a plane. She loves sports too. Liduška can skate, ski, ride a bike, hike in the mountains... She's a sweet girl who can sometimes dig in her heels and make her opinion heard. Just like any other girl.

The Bobath concept in therapies for children with Down syndrome

Veronika Kristková



The Bobath concept is one of the world's most recognized concepts in child rehabilitation. Its originators were husband and wife Karel and Berta Bobath, a physician and physiotherapist respectively, who developed a new framework in the 1940s and 1950s for assessment and treatment for patients with neurological movement disorders, especially children with cerebral palsy and adults after stroke.

The theory and practice behind the therapy

After performing a detailed assessment and analysis of the child's movement, the therapist works with the parent(s) to put together a therapeutic plan and goal to be reached. The therapist takes the activities the child is already doing and modifies them using specific techniques to enable the child to engage in typical movement. These techniques are primarily intended to optimize the child's muscle tension and help them make the movement as economically as possible, without unnecessary effort or pathological compensation models. The therapist does not perform the movement for the child, but merely offers the opportunity to acquire new sensory--motor experiences and learn a new movement skill. The first focus is always on what the child can do alone and how that can be used in therapy.

The therapy is highly functional (practical), focusing on movement that occurs in everyday life. The goal is not to achieve or improve certain movement patterns, but rather to encourage the child to cooperate more and more fully in everyday activities.

In addition to addressing the child's disrupted movement abilities, the therapist should also spend time on other aspects such as development and stimulation of sensory reception, perception, cognitive abilities, communication, and food intake (self-feeding). It is important that the therapist considers the child and their challenges at the present time while also anticipating the child's future, in five or ten years, and target their interventions accordingly.

Teamwork

One of the key aspects of the Bobath concept involves teamwork that keeps the child and family at the center as the focus and main team member. Most often they are in contact with a physiotherapist, occupational therapist, and/or speech therapist. Since child rehabilitation is extremely broad and covers a number of different aspects, the team should also include other experts, such as a psychologist, specialist physician (neurologist, orthopedic specialist), social worker, prosthetist, and vision therapist. All team members should be kept informed of the child's current state including abilities and restrictions and should all work to achieve the same end goal.

The Bobath concept in therapies for children with Down syndrome

Home-based therapy

The Bobath concept does not involve specific exercises or particular therapeutic elements as is typical with other methods. Parents receive instruction on **handling** for manually guiding the child's body and stimulating particular movement patterns during everyday activities like feeding, carrying, carrying out hygiene tasks and daily living skills, and playing. This handling should be applied throughout the day. For some parents this can become something of a problem. They often want to be assigned some particular exercises and told when and how many times per day to perform them. A Bobath concept therapist can explain to parents that stimulating movement patterns in everyday activities is, in fact, constant exercise that helps maintain the results achieved in directed therapy and also teaches the child new skills to use in everyday life.

Who is the Bobath concept intended for?

While the Bobath concept was originally created for children with cerebral palsy and adults after stroke, it can also be applied to any (primarily) neurological movement disability. There is no upper age limit, and the version of the concept for newborns and infants is called **Baby Bobath**.

The Bobath concept in therapies for children with Down syndrome

As mentioned above, the Bobath concept can also be used for conditions and disabilities other than cerebral palsy. The Bobath concept is an excellent choice as one of the first choice therapies for children with Down syndrome for a number of reasons. The Bobath concept techniques can significantly improve muscle tension in children with Down syndrome, who are often born with low muscle tone.

Other stimulation helps increase afferent (incoming) signals to the joints, muscles, and receptors, thereby improving perception of specific segments of the body and leading to an improvement in overall body schema (awareness). The therapy pays attention to **correct alignment** of the body. This means the movement takes place in high-quality patterns to protect against secondary complications (for children with Down syndrome this might involve kyphotization – creating an excessive curve in the upper spine).

The therapy focuses on everyday activities, always considering the age and mental abilities of the child. This functional therapy helps build independence and self-sufficiency in children with Down syndrome. When they get older, they are then less dependent on the care of another person. Experts work with the child as a team, usually consisting of a physiotherapist, an occupational therapist, and a speech therapist. This covers most aspects of care in which the child with Down syndrome needs assistance: movement (verticalization and locomotion), everyday activities (playing, hygiene, getting dressed), communication, and food intake (self-feeding). The advantage is that all team members are working toward the same goal and respect the current priorities of the family and child.

The Bobath concept is based on the principles of motor learning. With each new movement and repetition in many different variations, the child is constantly learning and can transfer the skills acquired in therapy more quickly and easily to use in everyday life.

When to start

Babies with Down syndrome can start the Bobath concept at birth. Unlike other concepts and methods, the Bobath concept teaches parents correct handling – specific ways of positioning, carrying, feeding, changing diapers, and playing with the baby in order to achieve targeted therapeutic results considering the current needs and abilities of the child and expected development in the future. Clinical experience and practice shows that children who undergo functional therapy according to the Bobath method achieve independence and participation in everyday life earlier and to a greater degree.

Conclusion

The Bobath concept is suitable for therapy in children with Down syndrome. It helps them improve their current state of health, develop new abilities, and become more self-sufficient and functionally independent. The Bobath concept should be one of the first choice concepts for therapy in children with Down syndrome.

The Czech Association for Children's Bobath Therapists (CADBT): www.cadbt.cz

Reflex locomotion (the Vojta Method) as part of physiotherapy for children with Down syndrome

Denisa Polanská



Babies with Down syndrome are often born with hypotonia, or low muscle tone, as well as hypermobility, or very flexible joints ("double-jointed"). These two factors play an important role in delayed motor development. Basic motor functions, such as lifting the head and chest while on the tummy, rolling from back to front, crawling, sitting and walking, are often delayed. The walking pattern also differs significantly, with the gait being unstable and careful, which can lead to slower speeds and shorter steps.

A difference appears in the quality of executing movement models in individual phases of development as well, which often leads to suboptimal posture, scoliosis or flatfootedness. These differences are typical for children with Down syndrome.

We can enrich the reduced or blocked mobility of children with Down syndrome using a system for activating reflex locomotion models called the Vojta Method. Reflex locomotion models contain partial motor patterns that lead to standing up and walking. This makes it easier for the child to move and communicate and improves the quality of the movement as well.

In addition to movement, the Vojta Method also has an impact on fine motor skills in the hand and orofacial area (mouth and face), which in turn improves food intake and digestion.

For these reasons the Vojta Method should be incorporated into physiotherapy for children with Down syndrome.

After the baby is born, you can start using the Vojta Method right away. This applies generally to all babies unless the Vojta Method is counterindicated. The physiotherapist will choose the specific exercises to be done.

Babies with a heart defect **always** require the approval of a cardiologist. **Only a cardiologist** can determine whether the Vojta Method is suitable for a baby before a heart operation and when (and if) to start applying it after the operation.

Therapy aid tip: www.rehabilitacnipodlozka.cz

The Vojta Method *is a diagnostic and therapeutic principle used with children (and adults) who have cerebral palsy. The idea is to elicit reflexive movements as a response to stimulation of precisely defined points. Reflex locomotion activates the central nervous system and encourages innate physiological patterns to resurface and consolidate after being suppressed due to pathology in the central nervous system. Czech neurologist Václav Vojta pioneered the method in the 1950s based on his own observation and clinical experience.*

Source: KOLÁŘ, 2010.



Occupational therapy is not just about playing

Zuzka Šimonová

Occupational therapy is one of the key rehabilitation areas we see more and more often in caring for children with Down syndrome. For children, occupational therapy takes the form of games and fun activities that target self-sufficiency and independence. But the occupational therapist is not just there to play with our children. Their role is very specialized. They have diagnostic and therapeutic tools to help isolate weak areas in the child's development or current abilities and focus their care and attention on those areas in particular. They can guide parents in choosing the best activities for their child's age and developmental stage. They can show parents how to motivate their child to achieve a goal. Occupational therapy can also give parents tips for toys or aids that might be helpful.

Why is regular playing at home not enough?

Any parent could argue that their child knows how to play on their own or with siblings. That is correct, of course. Occupational therapy for children uses play as one of the means of achieving therapeutic goals because play comes naturally to children. In occupational therapy, play is directed in a targeted way, using specific aids as well as ordinary household items, always with a specific aim: to support **the development** of gross and/or fine motor skills and **cognitive function** (attention, memory, spatial orientation, self-expression, etc.). The ultimate goal is to build the child's independence, self-sufficiency, and self-reliance, which will become the pillars of their later life. The occupational therapist helps build foundational self-feeding habits (preparing food and eating) and self-reliance in daily hygiene tasks and getting dressed without assistance.

Children usually go to occupational therapy once a month, or more often for younger children. The therapy sessions



are typically quite varied and usually offer a balanced program focused on, for instance, manual dexterity (such as practicing different types of knots), hand-eye coordination, or practicing asymmetrical movements. All this lays the foundation for body awareness and control.

What does "sensory integration" mean?

This somewhat technical sounding term refers to a therapeutic approach that **helps connect all the senses**. We can only function in daily life if our senses are correctly integrated. If sensory integration does not work the way it should, the learning process gets disrupted. The brain cannot process the incoming sensory information the way it needs to, so it is not able to send out the appropriate responses. Sometimes this means the person is not sensitive enough to stimuli (hyposensitivity) and sometimes it means they are too sensitive to stimuli (hypersensitivity). In the first case the person is usually passive, as if in a dream, unable to actively cooperate, with "undernourished" senses, etc. By contrast, hypersensitive people often experience intolerance to touch, light, and/or sound. They are riddled with anxiety and avoid many common situations (such as crowded events). Children with disrupted sensory integration have difficulty with fine motor skills and coordinating their movements, which also affects their ability to communicate. They often have difficulty concentrating, writing and reading.

Occupational therapy for children with DS

Occupational therapy for children with Down syndrome has a few key challenges, but they are not severe and can certainly be overcome. The most important thing is to understand that not all children with the same diagnosis will have the same level of knowledge, traits, personality, or even temperament. Each occupational therapy session must be customized for the particular needs of the child. When working with children with Down syndrome, the therapist's approach plays a key role, whether that means the occupational therapist or the parent acting as therapist at that moment. They need to have carefully thought through the needed steps and goals, and to be prepared, consistent, and patient. This package is the most basic element of achieving any goal.

For children with additional needs, it often takes very little to get their attention and help them concentrate on learning. Sometimes a slight change of environment will do the trick (turning off the television or music, putting away other toys/aids that are distracting them). Sometimes the parent might inadvertently choose an unsuitable activity that has no chance of holding the child's attention. Perhaps it is too difficult and the child takes the easy way out and gives up. Sometimes it helps to have a different person with a different tone of voice, intonation, words, etc. The occupational therapist can help parents with this as well. As a bonus, if the child is accustomed to working and cooperating with another person (authority figure) from an early age, that experience will prove valuable later on in preschool and school.



Occupational therapy is not just about playing

Common challenges in caring for children with Down syndrome include hypotonia (low muscle tone), which leads to the arms and legs not working in the correct movement patterns. The brain also may not receive enough stimuli, so different tactile surfaces (a tactile walking path, etc.) may help give children the input they need. Children often struggle with bilateral coordination, meaning both hands working together. One hand is typically more dominant, which in practice means that the child uses one hand to hold an object in place and the other hand to manipulate the object. Poor three-dimensional space perception, especially depth perception, causes significant problems that appear in activities such as difficulty walking down stairs. Children with Down syndrome often have difficulty applying skills gained through practice in general (real) situations.

The good thing is that none of the things mentioned above are impossible to overcome. If the child does not have any of the health complications commonly associated with Down syndrome, there is no reason to believe they will not be able to perform ordinary activities like working with both hands to string beads. Occupational therapy only works on activating and improving actions taken so that the play and later life can be as full and beneficial as possible.

The parent as occupational therapist

It should come as no surprise that the child's parents play the most important role in occupational therapy. They know their child best and are the best placed to assess their child's independence and self-sufficiency, and they should also be able to identify strong and weak points. This is for two reasons. The first is the most obvious – an independent, self-sufficient child will be less dependent on parental care in the future. As they say, train hard, fight easy. Children use what they learn in the early years through play for the rest of their lives. Ideally the elements of occupational therapy will become a regular part of your daily routine. An awareness of your child's weak points is also key for a balanced approach in caring for them. You want to connect things they enjoy and feel confident about with things that are new or challenging for them. That is the best way to ensure the child will find the activity both interesting and beneficial. Parents should not overestimate



or underestimate their child. They should bolster the skills the child has acquired while pushing their limits and setting new challenges and goals to build the child's self-confidence and self-assurance.

Occupational therapy has an incredibly wide range of content and possibility, but there is no reason to feel intimidated by it. It might seem full of technical terms and concepts, but it is not that difficult to get a grip on. The occupational therapist helps set the goals, but most of the work falls to the parents. If you use your imagination, you won't have much trouble achieving the therapy goals through your daily activities. I would say that for little ones, working at the table is the exception to this. It's not so much about what you're doing (stacking blocks, drawing, playing with playdough, doing puzzles, etc.) but about setting the space for work and following instructions. Working at the table and giving your child your full attention gives them intensive practice with patience, endurance, concentration, and willingness to cooperate. This lays the foundations in many ways for directed activities, which the child will encounter all through the educational system. Regardless of the child's temperament and interests, with regular and increasingly longer intervals you can set the foundation for all the cognitive functions a person needs to perceive the world around them and take part in it as well as they can. And that is what we all want, regardless of how many chromosomes are involved.



Vojta

Vojta - our sunshine

Vojta is our firstborn child. We were so excited to meet our new baby, wondering what color eyes he might have, who he would take after, and so on. The pregnancy went very smoothly; all the doctors said was that he was small. "At least I'll have an easier birth," I thought to myself. But then at 36 weeks I went to the hospital to register for the birth...

What happened next was absolutely insane for me as a first-time mom: "Your baby needs to come out right away. He's too small, you don't have enough amniotic fluid, and his heart isn't beating well." I was terrified. He really was tiny, at 1.71 kg and 42 cm. That day the pediatrician told us she suspected Down syndrome and a heart murmur or congenital heart defect. The next day another doctor told us our son had a complicated heart defect common in children with Down syndrome.

They transferred us to Motol hospital immediately, where we got a confirmed diagnosis of congenital heart defect and further genetic testing. It was one shock after another, and it took us some time to recover. And yet the instant my husband and I saw our baby boy, we knew he was our little sweetheart and we'd never give him up for anything. At Motol, the doctors were super helpful and told us about an association for families with children with Down syndrome. They assured us that despite what it might seem like, our baby would bring us a lot of joy. One doctor told us, "Be glad your baby **just** has Down syndrome. Some of the babies that come in here are much worse off." That was hard for us to hear, but she was right.

Soon I went to a meet-up of families whose children have Down syndrome, which really opened my eyes. I saw that all their children were laughing, talking, walking, feeding themselves, drinking on their own, and being independent – and that their families were happy. It was a huge load off my mind.

Since Vojta was 3 months old we had been trying Bobath therapy and orofacial regulation therapy. The

progress came along soon enough. Especially after the heart operation when Vojta was 6 months old. That brought a big change and a major step forward. We still go to rehabilitation appointments. We've been going to hippotherapy since he was 1. At first it was outpatient, but now we do a hippotherapy camp twice a year that does Vojta a lot of good. He always makes major progress when we're there. We've been doing speech therapy since he was 3.

With all this support, he's been developing really well. These days his little sister is giving him even more motivation to learn. She is 2 now, talking really well, and she's constantly telling Vojta something. She helps him and corrects him. When they play store together, she'll tell him, "Vojta, say it right: orange." He tries, but he doesn't talk as well as she does. He's made progress in speech since we started giving him castor oil, though. He can even put together simple sentences: "Mama, gi Vojta." That means: "Mama, give that to Vojta." Or, "Mama, Vojta want chocolate." Just five months ago that was unthinkable. He would just say, "Mama chocolate." And that was the end of it.

Vojta may be stubborn, but he's a smiley, cuddly little thing. He really loves hugs. He does have a temper, and he'll let me know about it if I say no or tell him it's time to stop playing and eat. Sometimes he might sulk for a few minutes, but soon enough he's his normal smiley self. He's loved books since he was tiny. We have a pretty solid library at home. When he reads on his own, he does great with filling in words, repeating rhymes, and singing songs. He also loves water. He could spend hours in the bath or in the pool. He loves gardening, so much so that sometimes the flowers and vegetables pay the price, but that's okay as long as he's happy.

Vojta brings us so much joy. He's our little sunshine. My husband and I are proud parents, and ever since we've had him we see the world through different eyes.





Early speech therapy in children with Down syndrome

Lenka Němečková

The general perception of speech therapy in the Czech Republic remains as a field focused on correcting pronunciation in preschool children. However, speech therapists work with people of all ages, from newborns to senior citizens. Their work extends far beyond exercises to improve articulation. Speech therapists work with babies where there is a risk that speech development will not take place naturally for whatever reason, with children who do not speak or do not understand speech in the scope appropriate to their age, and with children who have voice or hearing disorders or problems in the orofacial area.

Children with Down syndrome are typically born with several characteristic traits that can have a negative impact on feeding and developing the skills needed for speech development. These typical signs include low overall muscle tone, a high and narrow hard palate, difficulties with strength, movement and coordination of the jaw, tongue and lips, respiratory problems, and associated disorders of sight and hearing.

For all the reasons listed above it is a good idea to **begin speech therapy and physiotherapy in the first few weeks of the baby's life**. By working with a baby in the early days, a speech therapist can help monitor progress and guide speech development. With the speech therapist's guidance, parents learn to give their baby stimuli appropriate to their developmental level in the optimal order.

The specific focus of speech therapy and recommended activities are always tailored to the individual. Generally speaking, this involves techniques that influence feeding quality, oral-motor skills, communication and speech development.

Making speech therapy a priority

Zuzka Šimonová

It is unfortunate that speech therapy gets shifted far down the list of priorities in the first months, often years, of caring for children with Down syndrome. Intervention focuses on developing gross and sometimes fine motor skills, which of course closely relate to speech therapy. However, speech therapy itself tends to get attention when speech fails to arrive on time. Usually the child is already walking by that point, and parents have the chance to pay attention to another aspect of their child's development. People often have the incorrect understanding that speech therapists only step in to solve speech problems and teach children correct pronunciation. In other words, the first visit comes when the child is already speaking and needs to improve.

It seemed right to us to visit the speech therapist as soon as possible to give them a chance to build a relationship with our son and lay a solid foundation for working together in the future. Our amazing speech therapist, with whom we've been working since our son was 18 months old, agreed. She gave us a number of tasks to work on as we move forward together. Some parents of children with Down syndrome might be hesitating over whether to go to a speech therapist or might have been told by the speech therapist to come back when their child has a problem with speech or when they are at least 3 years old. If that was the speech therapist's response when you asked them to take your child on as a patient, let that be a warning sign and consider whether this is the right speech therapist for you.

When you open your heart to them, you find a way to them

Nikola Chmelařová



My work as a clinical speech therapist can be quite demanding, but the smiles, determination and carefree attitudes of the children I work with give me the energy to go on. I give my energy to children with Down syndrome without thinking twice, because I know they will give it right back to me along with motivation to keep working. At times like that I know that what I am doing really makes a difference. Working with these children can be challenging sometimes, because they know how to dig in their heels and sometimes they don't want to work, but if you know how to approach them, you'll find a way to them. When you open your heart up to them and they feel that you care for them and enjoy your work, it isn't hard to win them over. **Sometimes it takes some time, as they won't accept just anybody, but once you're in, I'd say you're in for good.** Yes, children with Down syndrome come to our practice often needing help with speech and communication. Usually we work with them long-term, but noticeable progress is guaranteed, especially when the child enjoys working with the speech therapist and looks forward to their time together. When the child sees the session not as an obligation but as fun, both therapist and child can enjoy the time together.

That's how it went when I started working with Bernadeta. We've known each other for several years, and I'm still watching her development and progress. It took a while for us to find a rhythm together. At first she was pretty shy, refused to talk, and got "stuck" on tasks she didn't like. She didn't have the words to say it yet, and my job was to get on her wavelength and determine what she didn't like and why. I think we got the hang of it pretty quickly, though, and then our speech therapy sessions went like a dream. Bernadeta is a cheerful, positive little girl who never misses a joke. She does have a temper, but it never lasts for long. Now she can communicate what she does and doesn't like, and in many respects she's independent. Her parents and siblings work and practice with her at home regularly. They do it with love and always try to make it fun so Bernadeta enjoys it. I'm convinced that that is the key to success.

Developing speech skills in children with Down syndrome requires regular practice and work on all the areas involved, which largely falls to the parents to implement. As speech therapists, we simply show parents the possibilities and methods for working on speech and encourage them as much as we can to work with their children. When done right, it can be fun time spent together. Gamified speech therapy is perfect for children like this. There is no point forcing them to do anything, but you can help them build what they need while making it fun.

Working with children with Down syndrome is rewarding and fun, although it can also be draining. That said, I know my work makes a difference, and I am happy to have the opportunity to help these extraordinary children and their families make the most of their children's potential and learn to engage in society to the fullest degree, sharing their enthusiasm and joy with all of us. We have a lot we can learn from them as well. The path may be a bit longer and more challenging, but they can handle it – and with a smile on their face, too!



Signing with children with Down syndrome

Zuzana Sýkorová

Dad is playing with Bětka on the rug. Next to them are sitting two boxes full of blocks, toy animals, and figures of people.
Bětka hands her dad the horse-drawn carriage.
He asks, "What is this?"
Bětka signs "horse."
Dad takes the carriage and says, "Oh, it goes with the horse. Should we find the horse? Where is the horse?"
As he speaks, he ***makes the sign for horse when he says the word****.*
Bětka looks in the first box, but the horse is not there. She goes for the second box, but it isn't there either.
Bětka signs ***"no" over the box and then signs "where?"***
Dad finds the horse, hands it to Bětka, and she smiles happily. Together they connect the horse to the carriage.
Bětka puts a person into the carriage and continues playing with her dad.

When our daughter Bětka was born a few years ago with Down syndrome, we had a vague idea that she would need extra care in a lot of ways. We didn't really know what she needed help with and what kind of support she needed from us. We soon learned from books and experts we consulted that among other things, our daughter would probably need a lot of help developing her speech. She might not understand speech as well as other children, and she herself might not speak for a long time.

We looked for things we could do about it. We didn't want Bětka to have thoughts in her head that she wanted to share with us but had no way of doing so. We read books, searched

online, and asked our early intervention specialist and other experts we worked with. In the end we found signing. We read what was available and asked everybody we could think of. We loved the idea, so when Bětka was about 8 months old, we set out on our new adventure and started signing. And I think it was one of the best decisions we made at that time.

It took a fairly long time before Bětka started using signs herself. The first came when she was about 1 1/2, and by about age 2 she was using several dozen signs. At 4, when she started preschool, Bětka often used a combination of speech and sign. Signing helped her a lot at preschool, especially early on. They helped her communicate better with the teachers and other students. She was also able to take part in school performances where the songs and rhymes were accompanied by signs. We observed her progress with joy: at 4 she signed a little to the songs, at 5 she signed and once in a while used words, and before starting first grade at 6 she was able to sing the whole song.

Bětka's little brother was born when she was about 2. Since he grew up in a home where signing was used, he naturally began to use it himself. It was his main communication method until he was about 18 months old, at which point he switched to spoken language.

What is signing?

Signing is a way to communicate more easily with children who have not yet mastered spoken language. It helps children understand what people are telling them and gives them a simple tool for communicating before they begin speaking.

Signing means that we use signs while speaking and respond promptly to the child's attempts to use their hands to communicate with us.

Signing can be an extremely useful tool for children with Down syndrome. Usually they take a keen interest in the people around them, watching them and making eye contact. Some even have a talent for imitating the movements, gestures and facial expressions of the people around them. At the same time, children with Down syndrome often experience speech delays. Many such children can do everything an 18-month-old, 2-year-old, or even older child can do, yet speak very little or not at all.

If we wait too long for them to start talking, we run the risk of wasting the critical window when they need to start trying to communicate with us about basic things. The time they want to tell us they saw a bird sitting on a branch, or they heard an ambulance siren, or they remember the yummy candy they had that morning, or they want to go on the swings, or they don't know where Grandma is but want to see her…

Children who want to communicate something to the people around them but have no way of doing so usually try for a while anyway. When they go too long with no success, they look for other ways to communicate, although adults might not like the methods they find. They might scream, roll around on the ground, hit or bite. Alternatively, they might avoid people and learn to be self-sufficient, playing on their own and experiencing their joys and sorrows alone. Neither one of these paths is ideal, as both lead to increased isolation, unhappiness and frustration.

If a child with Down syndrome is not talking, or not talking enough to build and sustain social bonds and express their needs, **we should actively look for ways to help them**. Most importantly, we should focus our attention carefully on the child, take note of their behaviors, observe and try to work out what they might be trying to tell us through those behaviors. The idea is to use the child's behavior to recognize what they are feeling, their mood, to show that we understand what they are experiencing, and to try to figure out why they feel that way. When a child is screaming and crying, for instance, we might check whether they are in pain, hungry or thirsty, cold or hot, startled, looking for attention, need us to hand or get them something, and so on. We start there, the same as we do with any other young child.

With Down syndrome, however, we can expect a child's understanding and active speech to be delayed, and so we should offer them more support. We should give them a communication system they can understand and use before they master spoken language. The system might be made up of multiple parts that work together to cover most of the child's communication needs. Signing should be an important part of that system. Other aspects might include the use of objects, photographs, pictures, or technology like a communication program on a tablet.



For most children with Down syndrome, however, signing is so beneficial that it should not be left out.

It has a number of major advantages over other alternative communication methods:

- It is not dependent on any external tools, so we can use it anytime and anywhere we have hands available: in the bus, in the bath, in the pool, while walking – and it's free.
- It capitalizes on the typical strong points of children with Down syndrome: it accentuates eye contact, watching each other, imitating the gestures, facial features, and movements of another person, and it allows close physical contact. You can even sign while holding a little one in your arms.
- Signing is as close as possible to spoken language, which makes it an excellent tool to prepare for spoken language. Signs have a limited time duration, so we have to observe the other person to understand what they mean. We can also adapt the sign to reflect how we want to say the thing. We can sign slowly or quickly, emphatically or gently, and we can make the sign big and clear or more subtle (in the same way as we use tempo, volume and intonation in speech).
- You can make signing into a fun game, which will make it even more engaging and enjoyable for young children.
- Adults typically find it easy and natural to combine ordinary speech with signing the most important words. This does not disrupt or change the way we usually speak with children.

Signing is essentially using gestures and signs (hand movements) along with speech. The adult talks and includes the signs (makes the motions) for the most important words. You might say: "Let's put on your hat to go outside," and as you say the word "hat" you also put your right hand on your head. **A child who is not talking yet uses signs on their own. A child who is working on mastering speech uses signs together with speech, usually when the people around them do not yet understand their speech fully.**

Which children does signing typically help?

Signing can help any child whose spoken language does not yet allow them to build and maintain social bonds and express all their needs in a comprehensible way. We can use signing with children who have diagnosed speech delay or any child in whom we can expect a speech delay.

Signing is suitable for all babies; some parents use sign as a support for speech development even with children

who have no speech delay. If your child with Down syndrome has younger siblings, you can use sign with them as well and it will benefit everybody.

You can start any time. Even with a small baby you can use simple gestures to communicate that now is time for milk or time to sleep. Some research recommends beginning to use signs for babies with Down syndrome at around 8 to 10 months. The earlier you begin, the more easily and naturally you and your baby will become familiar with signing and learning signs. On the other hand, some parents find it difficult to persist in using signs when their baby doesn't seem to be responding. Some parents may start signing at 6 months and their little one may not use any signs for a year or more. That leads some parents to stop signing for a while and then go back to it when their little one is a year or two old. It is never too late to start. If your child does not understand people around them because of a speech delay, you can still start signing. Even if they're 15. Adults can start using signs as well. The only thing that matters is whether signs help them communicate with people around them.

It's a good idea to choose a few signs to start out with (between one and five) to indicate things that are important for your child and that get mentioned multiple times a day. We recommend starting with what your child likes and finds interesting. That might be food, animals, signs associated with their favorite activities (playground equipment, coloring, looking at books…). The signs for "more" and "done" are also good to start with, because they let little ones regulate a number of different things that are happening, so they get a lot of use and little ones typically pick them up quite quickly. The first signs should be simple motions that are easy to see, understand, and reproduce. Symmetrical movements (like tapping the tips of your fingers on both hands together in the sign for "more") and touching body parts (like touching the mouth or head) also work well.

Especially at first, the main benefit of signing is that it gives your little one a chance to understand you better. By adding a sign to the most important words you say (often a sign that looks somewhat like what you are talking about – like a hat), you show your child clearly which word is the most important for understanding. At the same time, whether intentionally or not, you will likely say the word more clearly or emphatically. This helps your child understand what you are saying better.

With children who make good eye contact, watch the people around them, and pay attention to their movements, we should capitalize on that and use signs as often and as naturally as possible. Simply incorporate signing into the ordinary things we say to our children (adding a sign to the words we say):

"Okay, sweetie, time to eat!"
"Daddy is at work right now. When he gets back, we'll go outside together."
"There, now one more bite."
"Do you want to swing?
Do you want more? Yes?"
"Do you hear that? That's an ambulance siren."
"Look, there goes a train."
"Look, here's a picture of a car."
"Where is the cat?"

Adding signs to children's songs and nursery rhymes is also a great idea. Children usually love it and enjoy signing with you. It's also great practice to sing and sign "Rain, rain, go away" ten times in a row, because you'll probably remember the sign easily when you're outside and it starts raining. Your hands will get used to signing and you'll be able to use them more easily and automatically. Siblings and other children usually enjoy joining in for songs and nursery rhymes. You might even find a children's class in your area where they combine songs with movements.

If your child does not make eye contact often, does not try to imitate children's games (patty-cake, say bye-bye!), does not watch others or imitate their movements, and is no longer a baby, you might need to use some special techniques like those used in **ABA therapy**. If that is the case, **contact a speech therapist, early intervention specialist, or a clinic that uses ABA therapy** and can help you incorporate signs into your communication with your child.

If you start signing, you may well keep signing for a long time – months, years, or even the rest of your life.



There's really no telling in advance. How much will your child take away from it? That depends on whether you and others offer interesting signs to use, whether you keep adding more signs, and whether other people around you also learn to sign with your child. Siblings or other family members who love your child and spend time with them. Maybe your child's preschool or school will start using signs as well… The more people you get involved in this amazing project, the better. It doesn't matter much if people make the signs slightly differently. What is important is the desire to understand. You can ask the teacher about the new sign your child must have learned in school, find out what it means, and add it to your sign vocabulary at home.

If your child's spoken language starts taking off, you will probably quickly stop using signs. Make sure not to rush, though. Imagine a child who has learned and actively uses 200 signs and currently uses 10 spoken words. If you stop signing completely, your child will not have the chance to learn and use all the signs they would have acquired in the time it takes to learn to say the words for all 200 signs that they know. And that might take a year.

That's why we recommend that you keep signing even when your child starts talking. If your child has replaced a certain sign with a word that you almost always understand, it is all right to stop using that particular sign. You will probably find that your child will stop using the sign on their own and only use it again when you don't understand what they said.

As long as signing is accompanied by speech, the child's speech development will not be delayed by signing, even if they already know and use the particular words being signed. In that case the child will focus on the speech and not pay attention to the signs.

Who can help you with signing and where can you find information, materials and more?

- Ask a **speech therapist** or **early intervention specialist** for advice and support. For older children you can get information **in a special education center (speciálně pedagogické centrum), preschool or elementary school that works with children with additional learning needs**. Look around to see if your area offers any **classes for signing with children** or classes that incorporate signing. Some early childhood centers offer that kind of support.

- You can use **books about signing with children** (Terezie Vasilovčík Šustová: Jak se domluvit s kojencem a batoletem; Monta Z. Briant: Základy znakové řeči pro miminka).

- Babysigns has a lot of material to offer: www.babysigns.cz

- You can use **sign language videos for the deaf** to expand your vocabulary as needed: www.spreadthesign.com

- And for more information about signing, look for websites, articles, videos, comments, discussion threads or forums, and groups using search terms like **"signing," "baby sign," "signing for toddlers"**.

Signing as a bridge between us

Zuzka Šimonová

We see signing as one of the key aspects in caring for our son Vítek. It gives us a way to promote communication and avoid any number of misunderstandings and miscommunications and the frustration that comes with them. In a few weeks Vítek will be 2 ½ years old. He does not speak yet, but he has several dozen signs to help him express what he does or does not want or need or whatever else he wants to say. I feel that signing has allowed us to avoid outbursts of anger or frustration when Vítek wants something but has no way of expressing it. Instead, we get to have so many unforgettable, joyful moments, like when Vítek signs the chorus of his favorite song at bedtime, or when he signs to let us know that he wants this or that particular episode of his show. He gets incredibly happy when we understand what he wants, sing him the song, or put on his favorite show. We see signing as a bridge between us to help us connect until Vítek learns to speak in words.





Sára

Sára – our little fighter in pigtails

"Play Mozart for her. That's best for the brain," my husband told me repeatedly through my pregnancy, envisioning our daughter as a little Einstein. That's not all, of course – we were also planning how she'd be a top athlete. Or a world-class violinist! They were nice plans. But there was a little catch (or was there?). Our daughter Sára was born four years ago with Down syndrome. After we heard the diagnosis, we felt like we'd never have a normal life. We felt like it was the end and our dream of a healthy and perfect child was over. Fairly soon, of course, we realized that life goes on. We saw that life with our little girl was just as valid as if she had one chromosome fewer. We saw that our life was actually incredibly beautiful.

Sára is a little girl with pigtails who loves horses, her two younger siblings, her friends from preschool, singing, and all kinds of food. She's a spitfire, much more stubborn than her two stubborn parents, and a princess who loves playing with dolls on her bed or some comfortable couch. She dresses them, puts them to bed, or dances with them... And as the cherry on top, this little lady has one extra chromosome in every cell of her body. That chromosome doesn't determine who she is, like many people think, tossing everybody with the same diagnosis into the same pile labeled "disabled."

Sára hid her extra chromosome from us right up until she was born. Even after she was born, the hospital staff told us they didn't see any problem. They were right, really – Sára doesn't have a problem. It's us, our society, who see her syndrome as a problem. Sára has none of the conditions commonly associated with Down syndrome, thank God – her heart is totally fine and she gets sick less than any of the kids around us.

Sára – our little fighter in pigtails

Funny enough, it did occur to me while I was pregnant that my baby might not be entirely "normal" (although normal is a pretty relative term). I had plenty of people around me with some form of disability, yet no one in my immediate family was affected, but I figured it could still theoretically happen to me. I didn't like the idea one bit, but I told myself, "Let God's will be done. But not with the first baby, for goodness sake!" I still kept repeating to myself that nothing like that could possibly happen to us, since the probability was so low.

But it did happen. Firstborn and all. Like anything, it has its pros and cons... One of the pros is that we had plenty of time for her in the early days. I actually had so much time (she was a great napper) that I started a blog about life with her (www.sarinhlas.com). I wanted to shout to the whole world about how great she was and how lovely life with her was. I wanted to push back on our society's view of Down syndrome as a taboo and something to fear. Yes, of course some moments are hard. That's true for all children, though, not just ones with some sort of difference.

Sára is single-minded, easy-going, and veeery loud when expressing her disagreement. She is also incredibly empathetic, affectionate, and joyful. I love her hugs, bursts of laughter, finger plays, songs, and nursery rhymes. Her love for music and the guitar, her funny and surprisingly decent dance moves that are entirely unique and unrepeatable. Her shining eyes when we ask if she wants to watch her evening show or when she sees her friends from preschool.

Sára is in her first year of preschool at a children's rehabilitation day center in Ostrava. The first two weeks were challenging, as they are for most of her typically developing peers. Then the switch flipped and now she's upset on weekends that she can't go to preschool to see her friends, as she says. The center offers daily rehabilitation, speech therapy and occupational therapy several times a week, and of course preschool activities – music, art, dance. They celebrate holidays and birthdays, bake, go outside, play... Sára gets a huge amount out of the center in all aspects. She's starting to speak a lot better, she's more social, her gross and fine motor skills are improving... But most of all, she's happy there!

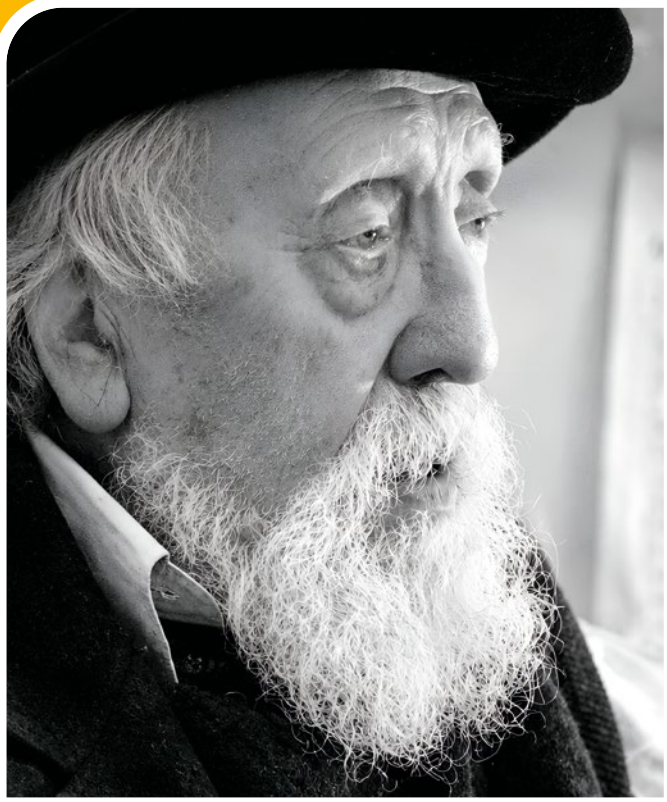
Her future is in the stars, just like that of any other child – no matter how many chromosomes they have. What can we parents do? Give our children a good foundation and get them ready for the future as well as we can. And most importantly, give them unconditional love. With our little princess that isn't hard at all... We love you so much, Sára.





Mediated learning experience according to Reuven Feuerstein

Irena Marušincová



Will my child be able to learn at least some things if they were born with this or that diagnosis? To what extent do their genetics determine and influence their development? How should I spend my time with them so I don't make their life more difficult as a parent? Should I leave them in their own world and not trouble them with the world I live in? Are they truly happy in their own world? These questions and many more run through the heads of probably every parent who has a child with any sort of disability. Israeli psychologist and teacher Reuven Feuerstein (1921–2014) had very interesting answers to these questions. He spent his life working with people with learning differences, and as close collaborator Louis Falik said, Feuerstein changed their fates entirely.

The secret of Feuerstein's approach lies in the way you interact and teach. As he saw it, from a young age people have two basic ways of learning: **direct learning exposure** and **mediated learning experience**. Direct learning exposure depends on the individual and whatever they notice in the world, how they assess it, and what they learn from it. In contrast, mediated learning experience puts **a mediator** between the learner and the world. The mediator helps choose relevant material, points the learner toward what is important, guides the learner in thinking about the context, looking for analogies, making generalizations, and so on. Simply put, the mediator teaches the learner to pay attention to the world around them, to learn, ask questions, and over time profit more and more from direct learning exposure as well.

Mediated learning experience is based on several different criteria and will not work without them. The most basic and essential are **intentionality** and **reciprocity, transcendence** and **mediation of meaning**. The mediator enters the interaction with the learner with a specific intention of what they want/need to teach them, while also responding to the learner as an individual, reacting to their answers, and modifying and guiding the interaction accordingly. Whatever is being taught must have some meaning for the learner. It needs to be important for them and have some transcendence into other areas of life. The mediator guides the learner in how to use what they learned in other situations as well.

Mediated learning experience is an incredible tool for helping all children and adults to learn, and people with Down syndrome are no exception. Children with Down syndrome are highly perceptive and open to learning, but they need a good mediator and a great deal of mediation from an early age in order to fully reach their learning potential.

Practice confirms Feuerstein's claim that chromosomes might not necessarily have the final say. Mediated learning experience is a proven way of opening people with Down syndrome to our world – a world they want to be in with us and understand – and for us to begin to understand their world, which itself gives us as mediators no small amount of enrichment.

Professor Reuven Feuerstein worked intensively with children and adults with Down syndrome. His grandson Elchanan, the son of his oldest son, was born with Down syndrome. The story goes that when he came to see his newborn grandson and saw the stricken and confused looks on the new parents' faces, he said: "What's all the grief for? Tonight we start planning his wedding!" At that moment he became Elchanan's mediator. He spent hours and hours with the newborn in his arms, maintaining eye contact and making all sorts of faces at him. These were not the ordinary games parents play with their babies. Feuerstein's goal was to teach the baby boy to focus his attention. That was the first of many steps that led to Elchanan growing up into a young man who made it through the regular school system, completed his military service (mandatory in Israel), and started living an independent life.

You can learn more about the theory and practice of mediated learning experience in the courses offered by Cogito, Center for Cognitive Education (www.cogito-centrum.cz).



Sources: COGITO-CENTRUM, 2021
STEINBERG, 2020.



What is a symbol?

Zuzana Križková, FIE (Feuerstein Instrumental Enrichment) instructor

"What is a symbol?" Bernadeta asked me once as I was getting a particular tool ready for her and mentioning the criteria involved. My heart leaped with joy and excitement. Not because she had asked a question with no simple answer. But more because she had asked about something she didn't understand, because she had asked right when the word appeared and she didn't want to go on without an explanation. She wanted clarity! That question at that moment symbolized something to me: that I was working with someone who was "with me," actively with me, with her whole being. We think together, create together, explore together. Work, activities, and especially the desire to understand, all together. Everyone who teaches or somehow engages in the process of learning with a child knows how important and valuable these attributes are – and how rarely they appear. How they transform the process of learning into a process of joyful exploration and contemplation.

FIE – Feuerstein Instrumental Enrichment

Maria Montessori (1870–1952) and Montessori educational theory

Alžběta Jantová



"The study of child psychology focused on the early years opens such wonders before our eyes that anyone looking at them with understanding cannot avoid a deep sense of excitement. Our work as adults does not consist in teaching, but in helping the infant mind in its work of development."

Maria Montessori

Maria Montessori was born on August 31, 1870 in Chiaravalle, Italy. She was one of the first girls to study at a technical high school. In 1896 Maria Montessori became the first woman doctor in Italy. Her life was characterized by an interest in underprivileged people. She fought for equal rights for women and against child labor.

After finishing her studies, she worked with children with mental illness or intellectual disability in the neurological ward of a psychiatric clinic in Rome. That is where Montessori's interest in education began. The caretaker who took Maria Montessori on complained that the children were filthy and greedy. She was under that impression because the children were playing on the floor with the bread they were given to eat. They made pictures out of the bread and then ate it – dirt and all. The room they were kept in had nothing but a bed, nothing for the children to entertain themselves. That was when Maria Montessori started thinking about how to support the mental and social development of these children. Upon observing their behavior, she concluded that the mentally delayed children confined to psychiatric clinics and institutions did not have only health-related problems, but that they also needed educational intervention. She helped some children so much that they were able to start attending regular schools.

She drew inspiration from French physicians and psychiatrists Jean Marc Itard (1774–1838) and his student Edouard Séguin (1812–1880). Montessori began using Séguin's tools with great success with children from the psychiatric clinic, and they remain part of the traditional Montessori toolkit today.

She presented her success stories with mentally disadvantaged children at an educational conference followed by a series of lectures in Rome. She took over as head of the



state school *Scuola Magistrale Ortofrenica* for children with special educational needs. While working at this school she worked on developing new educational aids, making notes, and creating tables. She believed that similar methods could help children without disabilities as well.

She gave birth to a son, Mario, who stood by her side for 40 years, from the age of 15 until her death. He continued in her work afterwards.

Maria Montessori's educational philosophy draws on the ideas of Rousseau, Pestalozzi, and European tradition. On January 6, 1907 she opened the first *Casa dei Bambini* (Children's House) in Italy. It served children living in poverty in San Lorenzo, a slum area of Rome. Montessori developed her educational method here, and eventually it spread to the rest of the world.

At that time she also converted to Catholicism, because she was surprised by the singular transformation in children at the Casa dei Bambini. Less well known is her concept for religious education, which she developed and practiced in the Children's House she ran in Barcelona. She died on May 6, 1952, in Noordwijk op Zee in the Netherlands.

Maria Montessori based her educational methods on solid theoretical grounds. The tools her method uses are carefully designed and crafted to support children's development. She spent a great deal of time simply observing the children as they worked.

The pillars of Montessori education include a prepared environment, a prepared guide (educator), respect for the child's developmental phases, independence and self-sufficiency, freedom and responsibility, order, isolation of quality, isolation of difficulty, and control of error. Montessori education can be applied from the very earliest age (from birth, or even before birth), and in recent years the same principles have been used in retirement homes as well. The method could be called universal.

Montessori materials fall into several different areas.

- In **practical life** the child learns how to care for themself and others, how to serve themself in order to be self-sufficient, and how to be useful for others.
- In **sensorial education** the child cultivates and engages their senses: sight, smell, touch, hearing and taste. They learn to use their senses to perceive what is important.
- In **language education** the child engages with words, communication, understanding language, and also learns to read and write at a young age.
- **Mathematics materials** allow the child to carry out complex mathematical operations, use their senses to understand varying amounts, and perceive the order that lies behind mathematics.
- In **cosmic education** the child learns about the world around them, near and far. They have the opportunity to see the connections between things, as the material is divided up into several easily grasped areas.

You can read more about Maria Montessori and her educational philosophy in her books.

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Dominička

Dominika – It's great!

It's been over three years since Dominika, our first baby, was born. After she was born, when the doctor told us she suspected Down syndrome, which was then confirmed two days later, we were both surprised. We couldn't really picture what that would mean in the future. For the first month we lived in our fears and questions. In the second month we shed our fears and had a lot of answers. And by the third month we had practically forgotten that there was anything different about Dominika.

We were incredibly fortunate in the excellent doctors at the neonatal ward at Bulovka Hospital, who were very kind and helpful. With their help, we found early intervention and an amazing pediatrician. We started having regular checkups right away, since Down syndrome does involve health problems and slowed development. We started regular physiotherapy as soon as possible, followed by speech therapy at 1 and hippotherapy at 1 ½. Yes, it was difficult for us, but we supported and helped each other, and that made everything go more smoothly.

We also learned to take joy in the little things. We celebrated every bit of progress Dominika made, however small. We met so many new, cheerful people, and things basically turned out great.

When Dominika was 1 year and 9 months old, we went to Jánské Lázně for treatments. I'm sure it was that



month of regular exercise that helped her start walking shortly after we got back home. We fell in love with the Krkonoše mountains, and we've been going there ever since as a second home.

A year ago, Dominika's little sister Natálie was born. It was rough at first, but now they're best buddies, especially when there's trouble to get up to.

We've always loved traveling and keeping active, and that didn't change even after Dominika and Natálie were born. We kept on taking trips. Now that Dominika is older, we're starting getting into sports. This summer we're strapping her into a carrier and heading out to hike around the mountains or go camping in our van. This past winter we tried snowboarding and skiing. It looks like Dominika enjoys both, which is great news for her and us both. We're already looking forward to warmer weather so we can head out on our bikes, balance bikes and scooters. All of those are relatively new for Dominika.

Dominika enriches our lives beyond measure and she's tons of fun to boot. If you're reading this and wondering what life with Trisomy 21 is going to bring you, don't be afraid! All you have to do is accept the challenge and you'll keep on enjoying life, plus you'll learn to celebrate even more often.

“These children energize me!”

Miloslava Stará, special educator



That’s what the parents of children with Down syndrome often heard as I spent years working with them individually trying to pass on the expertise that helped many children in their development. I loved the children and admired their desire to cuddle and make contact, and in many cases the results they achieved thanks to their parents and regular exercise.

It all stood on a foundation of the incredible love of a parent for their child, a desire to help them as much as possible in their development, and joy in every success, however small. I still admire the resilience, persistence, patience, and incredible selflessness of these parents. Children with Down syndrome (or other disabilities) play an important role in life and in society, since their existence inspires traits in people (especially their parents) that they had no idea they possessed.

My experience in a “research” classroom

The first class for children with intellectual disability was established in 1960 by former school inspector Anna Chvátalová on Náhorní street in Prague 8. It was called a “research” class and sat in a regular preschool.

I came to the class as a young teacher with no previous experience but with a great deal of interest in children with disabilities. There were about eight children in the class with a variety of visible disabilities. They sat in their seats and stared at me. All of a sudden one little girl ran over and climbed up on some play equipment next to the glass door. I was afraid she might fall and tried to catch her. She turned and threw her arms around my neck – she was a girl with Down syndrome! In that moment she won my heart, and children with Down syndrome and their fates have been part of my life ever since.

Social care benefits in the Czech Republic

Lenka Hečková

In addition to the usual social benefits like maternity benefit and parental allowance, or if certain conditions are met then also state social support benefits and assistance in material need, families of children born with Down syndrome are also entitled to social care benefits – **care allowance**, and benefits to support persons with disabilities – special aid allowance and **mobility allowance**. They can also request a **disability card (OZP card)** for their child that entitles the holder and escort to certain benefits, as well as a **disabled parking card OZP**.

Social care benefits and disability cards are not granted automatically; **you will need to request them using the correct form**, which is available for download from the Ministry of Labor and Social Affairs website (www.mpsv.cz/formulare) or you can pick it up at the Labor Office. You can file the applications when the child is **at least 1 year old**, or for the special aid allowance **at 3 years old**. Keep in mind that the benefits and disability cards are granted **for a certain period** only and you will need to apply again in the future.

These benefits can be of significant assistance to families, and families are legally entitled to them.

Children with Down syndrome and quality of life

Roman Cardal



1. The multifaceted concept of health

According to the World Health Organization, quality of life is determined by an individual's perception of their position in life in the context of their culture, and it includes other aspects such as their goals, expectations, standards, and concerns. The level of subjectively experienced fulfilment of these aspects contributes in a major way to the person's overall state of health.[1] This definition emphasizes the subjective experience of the individual, yet boundaries are also set that in certain cases make it possible to qualify the existence of certain people as not worthy of continuing. This also applies to children with Down syndrome, which many people consider a disability too great to permit an acceptable quality of life. As a result, they consider ending fetal development before birth to be an act of kindness that relieves them of the burden of a life of suffering and releases society from an unnecessary burden.

Many different factors enter into the definition of health, and by their very nature they do not fall under the purview of one branch of science. We can view the issue through the lens of medicine, sociology, politics, etc. Philosophy also has a place in the debate. This article makes space for the philosophical view, which no expert weighing in on the idea of human health should dismiss.

2. The philosophical view

First of all, the philosophical approach notes that establishing "quality of life" takes place on a general level. The definition should apply to every human. The general nature of the definition is tempered by the aforementioned emphasis on the subjective, highly individual experience of each person, but that does not counteract the universality of the concept. The opinion is expressed with a claim to general application that every individual is a co-actor in their own health as something that arises from their non-transferable mental and physical position in place and time.

And this is where the first complication arises. Are we really epistemically equipped enough today to make a definition on a general level? If the definition of health involves a strong subjective aspect, does the same not apply to our understanding? Is anyone today able to prove beyond a shadow of a doubt that human thought is objective and able to formulate certain, necessary, and generally applicable conclusions? No exact or empirical science has that kind of proof available, and a small probe into contemporary philosophy will also rid us of the hope of finding some reliable self-foundation of reason. Modern attempts in this direction have failed (Descartes, Locke, Hume, Kant, Husserl,

1. *Comp. WHO, 2012.*

Hegel), leading to the ever-present postmodern skepticism. If there is no generally accepted proof that reason is able to recognize objectively, certainly, necessarily and generally, how can we depend on the above definition of human health? The modern sciences are merely hypothetical, as they stem from unproven (and methodically unprovable) assumptions. Modern epistemologies have gotten lost in circular reasoning and ad infinitum regressions, a deadly trap lying in wait for anyone who asks about the final arguments for the scientific certainty of our understanding. Unless you can present an absolutely ironclad and infallible proof of the objectivity of human thought, intellectual honesty and consistency inevitably leads to the conclusion that the definition of health given by the World Health Organization is merely hypothetical, meaning it leaves room for other, alternative concepts. The objection that the established definition is verified in empirical practice does not hold up – the criterion of empirical testing lacks the necessary foundation, as it cannot be empirically tested itself. The requirement of critical philosophical reflexivity is unyielding.

3. A touch of much-needed skepticism

For that reason every discussion on scientific topics should be accompanied by a critical awareness of the ultimate groundlessness of the certainties of human reason.[2] That means that no scientific knowledge can be stated absolutely and it must always be placed into the wider context of the problem of the reliability of human rationality. That context is only available in rigorous philosophical reflections. Modern empirical science turns away from the question of the meaning of human life not because the answer is clear, but because it lacks the appropriate tools to find the answer. And yet the question still appears in some "scientific" conclusions, as it cannot be eliminated from human awareness. The claim that children with Down syndrome can be put to death before they are born is an example of a statement on the meaning of their life. Their existence is declared to have no meaning.

Yet no such statement should be made from positions that by definition cannot know anything reliable about the meaning of human life. If science in its current state cannot make any judgments about this issue, there is one serious consequence. If one does not know whether there is some ultimate meaning in human existence, one also cannot rule it out. The critical approach thus commands that scientific procedures must maintain strict neutrality in this matter. Logic demands that we accept the undeniable possibilities of the meaning of human life, which science currently lacks the resources to verify. They are out of its reach. Every scientist who values critical thinking should therefore anticipate the possibility that human life does have meaning, even though as a physician, biologist, neurologist, etc. they are not able to grasp this aspect of life in their thoughts. If we cannot recognize the meaning of life with certainty, we can also not recognize its meaninglessness with certainty. This means that it is possible that this hypothetically acceptable meaning includes people with disabilities. We then run the risk of ending lives that are meaningful.

Some would argue that children with Down syndrome are condemned to a life of suffering due to their disability, and so it is better to protect them from that fate by preventing them from being born. Anybody with even a little experience around people with Down syndrome[3] knows that this argument is invalid. People with Down syndrome can live their lives joyfully, and as this subjective awareness forms a key component of the definition of health, they cannot be viewed through the lens of false mercy. A great deal depends on the social environment in which they find themselves, of course, and whether they are accepted or rejected. It depends on the system of values inherent to

2. *We speak of the **groundlessness** of human thought from the perspective of modern exact science and contemporary philosophy, although that does not mean it can **never be grounded in principle**. Anyone interested in a cohesively presented proof of the objectivity of human thought can consult the work Illusions of Skeptics by Jiří Fuchs (FUCHS, 2015).*
3. *This author considers himself one of them, as he himself is the father of a child with Down syndrome.*

that society. For centuries the West valued the principle of solidarity with the weak, although it was not always applied equally in all circumstances. Modern ideologies built on the need to "revaluate all values" make a substantial shift in that principle.[4] Killing the weak is no longer seen as an inhumane act, but as compassion for the suffering.

There is another way to show how modern science cannot support killing children with Down syndrome: denatalism. According to the theory of denatalism, human existence is subject to so much pain and suffering that it loses all value. Not only the life of disabled people, but that of healthy people as well. We often see a noticeable asymmetry here. While many people with disabilities are able to take joy in their lives, no small number of healthy individuals are exposed to different types of trouble and pain that impair their ability to live a happy life. Their realistic view of existence and normal perception of the world is a source of suffering for them. No person born healthy is guaranteed to never encounter misfortune in life. In fact, the likelihood that they do encounter it is extremely high. The evils that can befall any person are beyond number. A tiny sample will make the point here: "According to Rummel… in the first 88 years of the 20th century 170 million (perhaps up to 380 million) people died by shooting, beating, torture, stabbing, burning, crushing, starvation, freezing, or working to death; others were buried alive, drowned… hanged, dismembered by bombs, or killed in countless other ways…"[5] There is no need to continue. Would it not then be better to carefully prevent the birth of healthy people? David Benatar thinks that it would. No modern scientist would be able to refute Benatar's position, as the problem is strictly philosophical in nature. And so a position exists according to which the criterion of distinguishing between healthy and ill individuals is highly questionable. The long and cruel torture of a healthy person, caused by other people or simply by unfavorable circumstances, annuls everything beautiful and enjoyable in their life before that. Moreover, it brings untold suffering to their loved ones. It would have been better if this person had never been born.

No scientific justification exists to support the killing of children with Down syndrome. What lies behind it is the unacknowledged "philosophy" that the right to life belongs to the healthy at the expense of the ill. And what is that conviction if not a declaration of the rights of the stronger, more capable and more able to adapt to life, and a denial of rights to the weaker? Do we really want to live in a society ruled by that concept of rights? We have enough historical experience to warn us against that. If we ignore the warnings, we must prepare ourselves for the possibility that we healthy people will one day be forced to bow to the will (or tyranny) of the stronger and more powerful interfering in our lives. The words of Leo Alexander, a physician who testified about Nazi crimes during the Nuremberg trials, should serve as a sufficient reminder:

"Whatever proportions these crimes finally assumed, it became evident to all who investigated them that they had started from small beginnings. The beginnings at first were merely a subtle shift in emphasis in the basic attitudes of the physicians. It started with the acceptance of the attitude, basic to the euthanasia movement, that there is such a thing as a life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Germans. But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the attitude toward the nonrehabilitatable sick."[6]

4. *One of the documents arguing for the need to reform Western culture through a "revaluation of all values" is Nietsche's The Antichrist: A Curse on Christianity.*
5. *BENATAR, 2013, p. 124.*
6. *ALEXANDER, 1949.*

Photo source: NOE, 2020.



Jiří

Jiří – I love being here

Several years ago some kind soul asked me, "How do you feel as a person with Down syndrome?"

I didn't understand the question. Or rather I didn't understand why they were asking. So I smiled and answered with another question: "I feel good, and how do you feel?"

No answer came, and it wasn't important to me after that.

What is important is that I feel like a person.

Honestly I have to say that I would feel better if there were fewer ignorant and uninformed people around.

Other than that I feel good in this world. I was born to good parents who always respected and loved me, so I grew up to be a self-sufficient and capable young man. I can do everything I need to do to live a joyful life. I am fully literate, which is very important for those of us with the gift of Down syndrome. I can express my thoughts in speech and writing. The ability to communicate with those around us is key. I follow the rules set out for me. I know that I have good manners and my behavior does not set me apart from people around me. And I'm not concerned about how I look. Well, that's not quite true. I do care about how I look – I always want to be well-dressed.

Now I will be very honest with you. I love people gifted with the same diagnosis as me. I want to help them as much as I can. But, if you'll forgive me, I feel better with people without a diagnosis. They understand me better (although not all of them), and I can talk with them about art, books, women, sports, and the God I love. They help me find solutions to my problems.

I am happy to be living on God's good earth and I don't understand why some people don't get that.



Jiří Šedý: Embrace; Hand

Hand – Jiří Šedý

A hand has magic powers.
Hope often means someone offering a helping hand.
My hand can touch someone gently.
My hand can hug someone and pull them toward me.
My hand can give a friendly pat on the shoulder
in encouragement, admiration or friendship.
My hand can gesture to call someone over to me.
My outstretched hand can protect someone from harm.
My hand can reject evil.
When I pray, I fold my hands to ask God and Jesus for help
and express my endless love, humility and faith.
My hand can guide someone who is struggling with a new task.
My outstretched hand can offer or request something.
My hand gives my body everything it needs.
My hand waves to say goodbye and shakes another's hand
to say hello.
My hand helps me achieve my desires, gifts, abilities,
and purpose in life.

My son Jiří

Every mother expecting a baby wishes for her baby to be healthy, smart, beautiful, well-behaved, and generally amazing. I was the same when I was expecting my little bundle of joy. And he was. My son Jiří theoretically met all my criteria, but there was always that "BUT".

Jiří was diagnosed at birth with Down syndrome (Trisomy 21).

I have to admit that I was shocked when I found out. The shock lasted a while, but I never even considered rejecting my son. I had plenty of support in my husband and eventually in my daughter Leonka, just one year older than her brother.

Right away I knew that I had to change my lifestyle. Slowly, one tiny step at a time, I started changing my moral values. Thanks to Jiří, I changed from a fairly superficial young woman to a woman seeking wisdom. The first major change was in my life philosophy. I found my strength in God.

I stopped fretting over little things. I learned to look for ways to improve my son's thinking and develop his overall personality. I stopped being so impatient and self-centered, always asking, "Why me?" Because I learned the answer: "That's why me." I learned to respect myself, to be bold in fighting against the myths about disability, which under a Communist regime were quite strong. I stopped attacking and learned to be gentle and kind.

I know that as long as I am alive our son will be the most precious person in my life, alongside my daughter and her family of course.

If someone asked me today if I would exchange our son for a healthy, successful man, I can answer with a clear conscience that I would not. Not ever. It's because of my son that I became a completely different person. It has certainly been a long process, but now I thank God for giving me the gift of a son diagnosed with Down syndrome.



Aneška

Anežka – Stories of dreams and wishes

Anežka is our firstborn daughter. We were so excited for her to be born, but then came examination after examination and then the news that our baby had Down syndrome and that we should decide whether to keep it or not. The doctor doing the genetic testing strongly recommended not, but my husband and I ruled that out entirely. The news about our daughter's diagnosis was a hard blow, but she was our baby and we would never let anyone hurt her. In the eyes of the doctor, we were crazy people who were ruining their own lives. How could he even say such a thing?!

Anežka was so eager to come into the world that she was born a month early. She was a beautiful, sweet baby like any other. Yes, her development was slower than typical. We waited a long time for the first signs of movement, and she took her first steps when she was 4. She started babbling at around 1, and despite her diagnosis and her delayed motor development, she started talking very quickly. By 2 she was making simple sentences and could have a conversation.

Her little sister was born when she was 20 months old, and her brother another 20 months after that. So Anežka had allies that pulled her along with them, although she had plenty to teach them as well – after all, she was the first to talk!

At 5 Anežka started preschool. At first she mostly observed the others, but slowly she started joining in the other children's activities and liked going to preschool. She made lots of friends, and still talks about her time at preschool today.

She started first grade (in a standard classroom) at nearly 8. At that time Anežka knew how to read and count to 10. She knew her colors, shapes, and could tell a simple children's story. She could also concentrate and focus on



what was going on for the whole class period. Her teacher admired that about her (maybe she didn't expect it?) and often told me how Anežka would help the boy sitting next to her find the right place in the textbook. Anežka has had a learning support assistant since starting 1st grade. Her assistant is an amazing woman with loads of experience who gets along well with Anežka and works well with the teachers, who respect her expertise. That teamwork is definitely critical for successful classroom integration.

The other children accept Anežka as she is, and she has friends in her class. It's true that there was a time when some of the other students were showing signs of unkind behavior towards her, but fortunately they were always caught in time (partly thanks to Anežka's younger sister, who was in the same class from 1st to 5th grade), and in the end relationships in the class evened out. The transition to middle school went smoothly, and Anežka moved up with the reputation of a good student who had no major problems. Her assistant is still working with her. Anežka has an individual education plan with minimal output, but she can work at basically the same level as her peers in all subjects except math. She likes school (although that does not mean she is always happy to study).

Now she is in 8th grade. Writing stories is one of her biggest passions. She has been a storyteller since she was very small. When she was just starting to babble and make sounds, she would often talk to herself in her own language that no one else understood. Her intonation and speech patterns really sounded like she was telling stories that no one else could understand. As we learned to understand her speech more and more, we found that she really did enjoy telling stories and putting into them everything she had experienced, books we had read and movies we had watched. Eventually we got Anežka to try writing



her stories down. We published her first book when she was 12. Now she is working on several more. Her stories are developing, but they are still largely a reflection of what she is experiencing, reading and seeing as well as her own dreams and desires.

She also loves reading and watching movies. She likes old Czech classics, but she'll enjoy a newer movie or one from another country too. She likes swimming and has no problem going out biking for a day or whole vacation with the family. She also goes to drama class, loves dancing and singing, and is learning to play the piano.

She is highly social, likes talking with other people, and has a quite sophisticated sense of humor.

We talked with Anežka a lot since she was very young, as we did with her siblings. Before she could read, we read to her – we still do, actually; evening read-alouds have become one of our family rituals. We played and still play games together, and we work on her cognitive functions together using the amazing Feuerstein Instrumental Enrichment method.

Thanks to Anežka we have met so many new people we would never have met otherwise. We have also expanded our education and our horizons. Simply put, she has opened so many doors we didn't even know existed before she was born. Most importantly, though, she is our child. She is good at some things and struggles with other things – that's normal. We are grateful for all three of our amazing children. We all belong together and we are glad to have each other.

A great worry, great protection, and an interesting doctor

Anežka Marušincová

Once upon a time there was an imaginary city. Well, it wasn't very imaginary, or it wouldn't be much of a story, would it?

In a run-down old house in that city lived Tonda and his older brother Michal. Their parents worked a lot and only took care of the boys in the evenings. Their dad worked so much that he got sick and then he was gone. Tonda knew he was just gone to the hospital, though. Even though Tonda was just 8 years old, he ran to the church and prayed for his dad.

Tonda found great protection with his friend and the friend's grandfather. The grandfather made healing drinks and slushies. He gave Tonda's dad one of those drinks and the dad got better. They had a saying about him in that city: "A good doctor is much better than death." That means that a person who saves sick people's lives is good.

When their dad came home from the hospital, Michal stopped playing computer games and Tonda stopped playing on his phone. They put their dad to bed, gave him his medicine, took pictures of animals for him (he was an animal photographer) and made sure he ate right. The dad got better after a few days and they all lived happily ever after.



Ten things we know from experience

1. You've learned that your baby most likely has Down syndrome. This very same baby might be the reason you experience beautiful things you can't even imagine now.
2. What will your baby be like? Your baby will be a singular personality with huge potential. They will inherit some of your character traits and be like you.
3. The most important thing for your child will always be knowing that they are part of a happy and loving family.
4. Your little one will not earn their place in this world through force of intellect and performance, but through the power of a smile that comes straight from the heart.
5. Make sure to see your child first and the diagnosis second.
6. Take each day as it comes. Take it with joy that you can be with your child.
7. Talk to your child. Make lots of eye contact with them. Your child's eyes are a mirror that will reflect everything that is most beautiful in this world.
8. Gather information, but don't overwhelm yourself or your child with it. In the early days the most important thing is being together.
9. Don't isolate yourselves. Make contact with people and meet up with other parents who have children with Down syndrome so you can share your experience, joys and worries.
10. Seek out people who will work with your child patiently and build up your child's self-confidence and joy in the skills they are acquiring and things they are learning. A solid therapist/child/family team works wonders.

Every person has beauty, value, and importance. Every relationship is unique and has healing power, the healing power of love.
(Jean Vanier)

We have you now. Finally we are together. You are maturing at your own pace. You thumb your nose at all the books that describe typical child development. But you have the most piercing gaze that has ever existed, and it looks right into our hearts. You can snuggle like no one else. You break every possible rule, and that teaches us about real life. Thanks to you we are learning to take life as it is, with patience and love. Otherwise it would slip between our fingers.
(Clotilde Noël, from the book Fallen from the Nest)

People gifted in this way can focus more on developing their hearts and learning about love, which no disability can limit.
(Jérôme Lejeune – – Little Sisters)

The meaning of life is not dependent on health or disease, but on the essential nature of man. Every human being has excellent existential prospects.
(Roman Cardal)

Without my daughter, I could never perhaps have done what I did. She gave me the heart and inspiration.
(Charles de Gaulle)

She is my joy and my strength. She is the grace of God in my life. She helps me to look beyond all the failures and honors, and always to look higher.
(Charles de Gaulle)

While we try to teach our children all about life, our children teach us what life is all about.
(Angela Schwindt)



The quality of a civilization can be measured by the respect it has for its weakest members.
(Jérôme Lejeune)

Every person can develop, every person can learn, every person has a place in the world, every person longs for fulfilment and meaning in life.
(Reuven Feuerstein)

These children do not fit into the logic of performance, but they are testimony to the beauty of existence.
(Fabrice Hadjadj)

Conclusion



Dear parents and other readers,
As we close we would like to remind you that there has never been a better time in the history of the world for a child to be born with Down syndrome. Now, there are countless resources available to help people with Down syndrome reach their full potential. Today people with Down syndrome can go to college, have careers, drive, get married, be public speakers, become actors and actresses, play (multiple) musical instruments, live independently, and live meaningful and productive lives.
True love doesn't count chromosomes. It sees beauty in all life.

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Spolek Trizomie 21 is an organization that provides families with contact information for experts and therapists.

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