



Annual Report

on the activities of “Downside Up” Charitable Foundation
July 2019-June 2020

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Dear Friends!

This year has been one of the most unpredictable for us all. The global pandemic has caused us to experience many changes and difficulties in our daily lives, at Downside Up however we have tried to embrace this situation as a challenge and an opportunity to learn new things.

“Downside Up” has steadily been developing online services for several years now and because of this we have been able to quickly restructure and continue to support our families remotely. However we are well aware of how difficult this situation has been for them and how many different problems have arisen. We are delighted that, in spite of everything that has taken place many families have been able to take advantage of our new remote format of support. Amongst many other activities children and teenagers together with our specialists online prepared for school, learnt to cook, to do yoga, to conduct a dialogue and take part in a discussion. Moreover, the remote format helped the children make new friends from across Russia. At the online festival “Different Planes”, children of all ages from different regions of Russia demonstrated their talents to four and a half thousand viewers. We want to say to both parents and children: “We are proud of your perseverance and your achievements!”

Public recognition

On April 14, 2020, the Vedomosti newspaper published a rating of Russian charitable Foundations, in which Downside Up came 14th.

The pandemic has also demonstrated that we have many loyal and responsive friends and partners who, despite the difficulties, continue to support us and for this we are very grateful! We feel the solidarity of our colleagues from across Russia and will continue working together to achieve qualitative changes in supporting families in our country.

This academic year also saw a continued exchange of experiences with foreign colleagues. Downside Up spoke at meetings of the European Association of Down Syndrome and at the World Down Syndrome Day International Conference usually held at the UN headquarters in New York but this year held online.

With your support we will continue our work and achieve the results that we share with you in this report. We will pursue all effective forms of work that this difficult time has made necessary. We sincerely thank all the families, friends and partners who help people with Down syndrome!

*Anna Portugalova,
Director of Downside Up*

About Down syndrome

What is Down syndrome?

- Down syndrome is the most common genetic abnormality in the world.
- It is not a disease. It is a condition determined by the presence in human cells of an additional, third, chromosome in the 21st pair of chromosomes. Each cell in the body of an ordinary person contains 46 chromosomes, and in the cells of a person with Down syndrome there are 47 of each.

How often are children with Down syndrome born?

- One in 700-1100 babies is born with Down syndrome.
- The birth rate of children with Down syndrome does not depend on their parents' lifestyle, health, habits, nutrition, wealth, education, or nationality.

How many people with Down syndrome live in Russia?

- According to expert estimates, **approximately 50 thousand people with Down syndrome** live in Russia, half of them **are children**.
- There are no official statistics on the number of children and adults with Down syndrome in Russia.
- Downside Up estimates that in Russia:
 - **o every day, six children are born with Down syndrome;**
 - **2000-2200 children are born every year with Down syndrome.**

What problems do people with Down syndrome have in Russia?

- During the work of our Foundation, the quality of life of people with Down syndrome and the attitude of society towards them have significantly changed for the better.

- At present most children with Down syndrome live in families, and the system of state support and education for them is actively developing. This has been facilitated by the work of our Foundation.
- We strive to ensure that people with Down syndrome develop their capabilities and reach their potential in all areas: in their studies, their creativity, in sport, in work and in communication.
- However, families of children with Down syndrome still face many different challenges at different stages of their lives.

Families raising children with Down syndrome

- **40 %** of families on being told their child has Down syndrome hear inaccurate information on the condition as well as being given the opportunity to abandon their child to an institution.
- **59 %** of families have difficulties trying to get their child into kindergarten.
- In the Russian regions, **16-21 %** of pre-school children do not go to kindergarten.
- In Moscow, **11 %** of school-age children do not go to school, and in the regions - **21 %**.
- In the Russian regions:
 - **33-51 %** of children do not receive free early intervention services;
 - **36-48 %** of children do not attend any clubs or other additional classes;
 - **30-34 %** of families are not aware of parent associations or assistance funds in their region.

Based on Downside Up research

About “Downside Up” Charitable Foundation

Registration date September 15, 1997

Mission: Downside Up is a Russian charitable organization dedicated to improving the quality of life of people with Down syndrome in Russia. We strive to provide high-quality professional services that ensure personal development, personal fulfilment, acceptance and inclusion of people with Down syndrome in society. Downside Up strives to ensure that people with Down syndrome grow up in families, study in educational institutions, are employed and given opportunities to socialize.

Strategic objectives 2017–2020:

- To promote the social adaptation and integration into society of children and young adults with Down syndrome.
- To promote the prevention of social orphanhood of children with Down syndrome.

What we do:

- We provide high-quality, professional services to people with Down syndrome and their families.
- We develop our own system of educational resources for specialists working with people with Down syndrome.

Social value of our activity

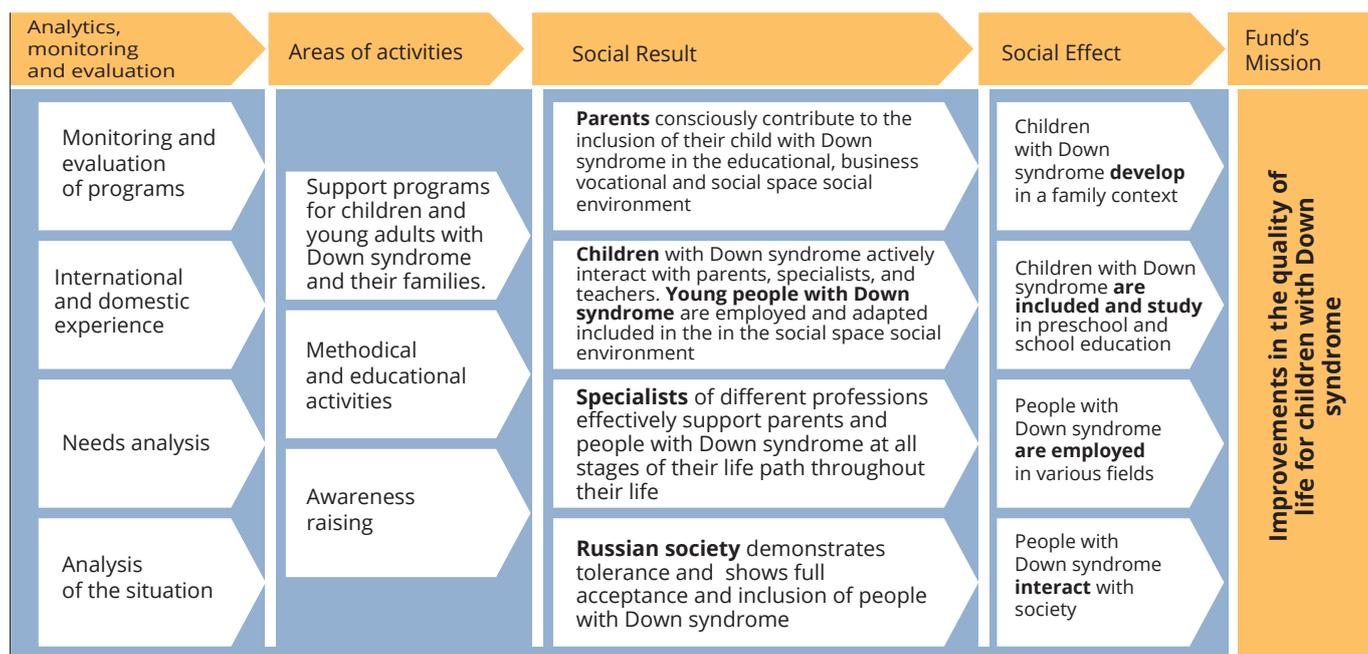
For more than 20 years Downside Up has been providing psychological, pedagogical and social services for children with Down syndrome and their families. A while ago we began to ask ourselves: “What is the social value of our activity?” Based on our mission and vision, we have formulated the social changes that Downside Up is striving for. Now the fund is trying to build all its work focusing on the formulated social results and effects. We pay special attention to obtaining systematic feedback from beneficiaries and other interested parties.

The principles of family support:

- We focus our attention on the whole family, not just the child.
- Parents receive support from the moment the risk of having a child with Down syndrome is established.
- Downside Up develops a system of face-to-face and remote services.
- All support for families is provided free of charge.

The geography of activities:

Downside Up is located in Moscow. For Moscow families, the Foundation conducts regular classes with children and parents, organizes events and holidays during the school year. Families from all regions of Russia receive Downside Up’s own methodological literature and the magazine “Make a step”. They also receive information and methodological assistance online. If it is possible for them, they come to face-to-face consultations, as well as take part in remote group classes and individual consultations. Russian-speaking families from all over the world can receive information and methodological assistance from the Foundation, as well as full-time and part-time support from specialists. Specialists from all regions of Russia and neighboring countries are invited to attend face-to-face and distance learning events and can subscribe to the magazine “Down Syndrome. XXI century” and receive a set of methodological literature.



The reporting year in numbers

8 780	4 901	1 301
families with children with Down syndrome registered on the Foundation's database	individual face-to-face and remote classes and consultations were held	group sessions were held for children and families
42	65	77
different groups worked with children and families	training events were held for specialists and parents	specialists received certificates of professional development
494	7416	36 850
students participated in face-to-face training events	students registered for distance learning events	copies of published books and magazines
8 190	3 647	66 500
copies of published books and magazines sent to families	copies of published books and magazines provided to specialists	a monthly average of users who visited the Fund's website (Internet portal)
365	610	23 354
new materials posted on the Foundation's website	new unique posts published on the Fund's social media platforms	new subscribers to the Fund's social networks
107	99 288 129	81 676 481
different articles about Down syndrome and the work of the Foundation published in the media	rubles raised	rubles spent

Remote work during the pandemic

(March 18-June 30, 2020)

On March 18th 2020, Downside Up suspended all face-to-face activities with families and professionals: all group classes, one-to-one consultations, educational and festive events went online. The Foundation continued working remotely for three months whilst simultaneously urgently transferring full-time forms of support online.

What did the self-isolation regime mean for children with Down syndrome and their parents?

Kindergartens were closed, and many schools were unable to establish distance learning. Children with Down syndrome, for whom regular and consistent work on reinforcing skills and socialization are vital, found themselves in an educational and social "vacuum" that adversely affected their development and psychological well-being.

Looking back, we can honestly say that the Foundation's team successfully managed to fully transfer its work from a predominantly face to face format to a remote format, not reducing, but expanding the number and range of services, as well as the geographical reach of families that it supports on a regular basis. As a result, the situation we find ourselves in has served to further unite the Foundation's employees into a close-knit team of likeminded people. Moreover and, most importantly, it has raised our interaction with families, children and adults with Down syndrome, as well as with our partners from the regions to a new level.

During the pandemic period

Downside Up teachers have developed a large number of new training materials for remote consultations and classes with children:

391 videos, including cartoons and children's fairy tales
185 different photo materials
96 presentations and manuals
191 text materials

Materials received from families with completed homework:

1840 videos, including performances, theater sketches, poetry cards, master classes and interviews
850 photos, including paintings in the framework of the flash mob "Art-Isolation"
45 texts

New forms of support for families, children and adults with Down syndrome emerged: an online Reading room and online communication groups for adults with Down syndrome.

In total, during the pandemic time:

764 individual consultations,
403 family and group lessons were held.

New remote methods and forms of group and individual lessons have been created and successfully implemented for most types of family support.

Now all forms of Downside Up support are available for families from anywhere in Russia. During this period, **more than 70 new families with children and adults with Down syndrome from different regions of the country and abroad joined the Foundation's group classes.**

Working remotely and implementing programmes created by Downside Up specialists was often even more individualized for families than face-to-face programmes. For example, after receiving a video task, parents were asked to work with their child, record the lesson and send it to the teacher. In response, the specialist gave feedback. Throughout the process our specialists support and guide parents. For many families, this style of work has been extremely productive and inspiring.

Initially, many families doubted that online support delivered by speech therapists and psychologists could be effective. However, it soon became evident that this model of support was indeed possible. During the lockdown we received a huge number of thanks from parents describing how remote support from Downside Up had helped their child, psychologically and in their general development in this difficult time.

Here are just a few of the dozens of thank-you letters we received from families in April, May, and June 2020.

REVIEWS FROM PARENTS

Valentina's Sister (Day Employment Group):

"Being in lockdown and completing teacher assignments, Valya began to speak in sentences. Every day she greeted her teachers and was reminded that she enjoyed cleaning. And now, thanks to the tasks she was given, she sweeps the floors in all the rooms, dusts, washes dishes, wipes them, makes the bed. We started writing words, reading and telling stories. Valya started painting, playing board games, and doing Nordic walking. She likes to talk to the teachers. Given Valya's age, these are great achievements. We never tire of saying words of gratitude to our teachers of the day employment group: Lada, Zhanna, Katya, all the employees of the Fund and to everyone who supports Downside Up. Without you, we couldn't have done it".

• • •

Alena's mom (School preparation group):

"Throughout the lockdown we were fully supported by our school preparation group. Remote meetings provided tremendous moral support, gave impetus and direction for action, helped to cope with unwanted behavior, be organized, avoid mistakes and incorporate learning elements into everyday life. We received a lot of materials: lesson plans and methodology for teaching reading, meetings with the psychologist, classes devoted to NUMICON and mathematics. We were able to learn about how other families live, how they cope, how the parents in our group resolve their problems.

Their experiences, their emotions meant a lot. After a month of lockdown, a huge change took place in Alena - she began to communicate. Just like other children she began to call out, ask and answer questions, complain. We have not had this for seven years, and it is a great joy. Thank you very much, <teachers> Liza, Nastya, Lena and Masha!"

• • •

Lizaveta's mom, about psychological support during self-isolation:

"We found the Downside Up website when we were having difficulties in communicating with our daughter during lockdown. We thought Lizaveta had autistic characteristics. My husband and I became very preoccupied, all we could talk about was her behavior. We owe a great debt of thanks to the psychologist Ilya, who provided us with advice. He reassured us and gave us useful strategies and relevant materials to read in order to deal with our daughter's behavior as well. Of course, in lockdown, it is difficult to provide a child with the same level of interest as in normal everyday life. My daughter even correctly used the word "boring", which she got from among the cards about emotions. Ilya recommended to take concise steps and actions, to encourage Lizaveta more closely in household chores. On the web-site's forum, I started communicating with speech therapist and early intervention specialist Marina Ivanova. I would like to thank Downside Up Foundation for the support provided to our family during this difficult time."

During and as a consequence of lockdown, several excellent and creative projects were instigated.

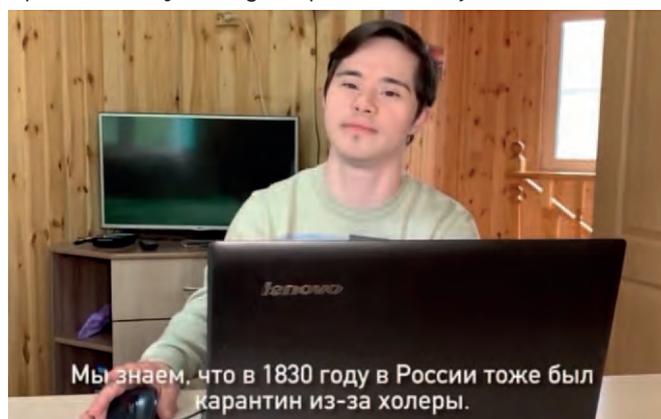
Examples of paintings in the framework of the flashmob "Art-Isolation", made by children from the Downside Up Theater workshop together with their parents as part of classes "Working on an artistic image".



Project "Poems for Victory Day 2020", performed by the participants from the Downside Up Theater Workshop:



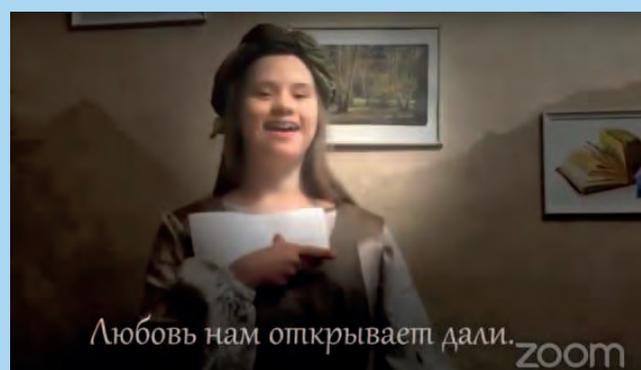
"Letters to Pushkin" - tasks for children from the Downside Up media Lab for the great poet's birthday:



On June 6, 2020, Downside Up held **the festival of creative inclusive studios "Different Planes"**. Unfortunately, due to the pandemic, the festival was moved online, however the advantage of this was that it allowed us to invite groups from across Russia to participate. As a result, 12 creative studios working in the field of theater, animated cartoons making and other forms of media from nine Russian cities took part in the festival: Irkutsk, Kazan, Kasimov, Kirov, Moscow, Pyatigorsk, Sochi, Ufa. The performances were broadcast on YouTube and Facebook, with the total number of views exceeding four and a half thousand. The participants from Downside Up's creative workshop were co-hosts on air and did a great job.

* * *

The sketch "Different faces of love" based on the poetry of Lope de VEGA - the result of joint creativity of children, their parents and teachers – is just one example of the projects presented by Downside Up creative studios at the festival.



Accompanying families

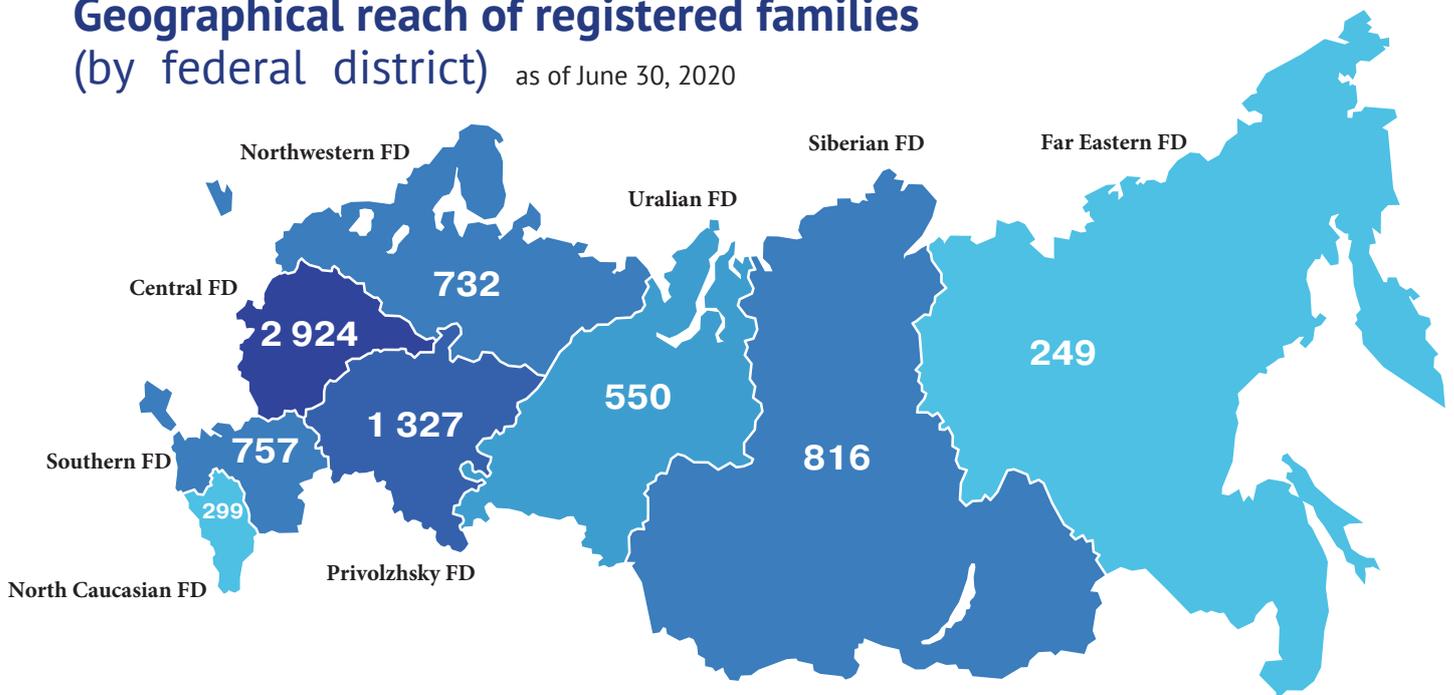
Psychological, pedagogical and social support of families has been and remains the main focus of the Foundation. As in previous years, the number of registered and supported families continues to grow. The geographical reach of families covers all the Russian Federation, as well as the countries of the former USSR in which Russian-speaking families live.

Number of families in Downside Up database

as of June 30 of each year



Geographical reach of registered families (by federal district) as of June 30, 2020



Total families from Russia: 7654

435 families from Ukraine, 217 - from Kazakhstan, 186 - from Belarus, 288 - from other countries.

REVIEWS FROM PARENTS

Eva's Mom:

"Dear teachers, You have become our family this school year!

Daria Chaklina, Tatyana Gerasimova, Elena Ilina, Svetlana Sumlennaya, Marina Ivanova, Vera Anatolyevna, Valentina Viktorovna, thank you very much for your caring participation in our life! We started visiting the Junior adaptation group in October 2019 and moved to the senior group a month later. Such a leap in development occurred in Eva only thanks to you, our dear teachers. And with each lesson, the development became more active. Training sessions are a storehouse of different skills and abilities. With the help of the game, you teach children simple and at the same time the most necessary things in their lives. You teach not only children, but also us parents to be patient, empathetic, caring for our children, and sometimes strict. You teach us to communicate with your own children. Dear teachers, you have so much love, concern, support, participation, you are a support for Eva and me and all parents! The school year brought a shock due to the quarantine, but the distance learning sessions you organized did not prevent further training. We looked forward to each task with such impatience and performed it with great pleasure. I want to say that the responsibility and imagination of parents has increased. Thank you for your tips, ideas, we have learned so much. All I needed was live communication with you, other parents, and, of course, the kids.

Music for kids is a unique project! An hour of classes passes in one breath, so enthusiastically children listen to the teacher. Tatiana, you are an authority for Eva, she has become more sociable, open to other people, music calms her and gives her so many positive emotions! Consultations of psychologists also did not pass without a trace. Mom's calm and confidence is in your hands!

And online consultations with speech therapist Marina Ivanova put everything on the shelves in my head. Now we live under the motto: "If you want to raise a child, raise yourself first!" Thank you, Marina, for the order of your thoughts and actions.

We wish you, dear teachers, good health, strength of mind, even more energy, creative and professional growth! You make the world kinder!

• • •

Yaroslav's mom:

"We have been visiting Downside Up for a consultation every six months. During this time, we work on the advice we received and prepare new questions. Our situation a couple of years ago: Yaroslav was 4-5 years old, it was impossible to walk with him, he ran away, did not obey, ignored, yelled. This behavior was typical at that time. And we attributed it to the syndrome and mental retardation. We endured and practically resigned ourselves, swore at the child, did not want to take him anywhere with us. And only at the consultation at Downside Up was it explained to us that the child does not see or hear us properly and therefore behaves like that. Now, thanks to the professional help of Downside Up psychologist and speech therapist, my son hears us, reacts to our requests in the street, in the kindergarten, in the store. I would not have been able to solve this problem on my own, and the child would have been at home, and the psychiatrist would have prescribed some medication for us. Two speech therapists refused us, even for decent money. Yar didn't want to study, he was spreading the office and other disgrace. A psychologist at the regional center for helping children with disabilities worked with my son, but did not give me tips on how to improve his behavior. It was only during the consultation at Downside Up that we received valuable information for us and were able to radically change the child's behavior at home, telling all family members how to behave. We even started going to a regular kindergarten."

• • •

Dima's mom:

"Dear, dear Tatiana Nikolaevna. Thank you very much for everything that you do for us. And today's meeting, very interesting and useful, and online classes, and speech therapy with Irina Anatolyevna, and group sessions with Tatyana and Anastasia, and the accompaniment of psychologist Alla Evgenievna - such a powerful support for us. Video assignments from Irina Anatolyevna are fantastic. I have long wanted to write to you about online classes, as it turns out, it works well. And in general, everything is great. We were very, very lucky with the teachers. Thank you very much".

Family Support: services for families, statistics on classes held in 2019/2020

Group Sessions on Psychological and Educational support

0–2 years	“Sandpit” – Psychological support sessions on parents-child interaction		25 sessions 28 families
1,5–3,5 years	Groups on Social Adaptation Toddlers learn to communicate with adults and each other during games and in various everyday situations. Parents act as assistant.		5 groups 172 lessons 88 children
3,5–6,5 years	Groups of Supportive Education Children learn to act independently, without parental support, to take part in group activities, games and everyday tasks, and to develop communication skills with their peers.		6 groups 214 lessons 65 children
6–7 years	Speech Therapy		2 groups 33 lessons 12 children
6,5–8 years	Preparation for School		5 groups 173 lessons 55 children
7–16 years	Adaptation to School		5 groups 139 lessons 55 children
13–16 years	Psychological support for teenagers		2 groups 43 lessons 16 teenagers
16+ years	Vocational guidance		1 group 30 lessons 11 teenagers and adults
16+ years	Online reading room for teenagers and adults	NEW!	1 group 18 lessons 17 teenagers and adults
18+ years	Psychological groups for adults		1 group 9 lessons 11 adults
18+ years	Day Employment Group		1 group 80 lessons 17 adults
18+ years	Online Communication Groups for Adults	NEW!	2 groups 14 lessons 17 adults

Psychological Group Sessions for Parents

0* – 1,5 years	Group sessions on overcoming the ordeal of having a baby with Down syndrome	9 sessions 51 families
1,5 – 16 years	Mutual support groups (held alongside group sessions for children and teenagers with Down syndrome)	442 sessions

*- including families expecting a baby with a high risk of having Down syndrome.

Творчество и активный образ жизни

1,5 – 3,5 years	Music for babies	1 group	35 lessons	24 children
3 – 7 years	Yoga	4 groups	100 lessons	25 children
7 – 10 years	Floorball NEW!	1 groups	10 lessons	21 children
8+ years	Theater workshop	2 groups	140 lessons	33 children
16+ years	Animation	1 group	39 lessons	6 teenagers and adults
16+ years	Media laboratory	2 groups	62 lessons	15 teenagers and adults

Individual support

(consultations with speech therapists, psychologists, early development specialists; as well as consultations of 2-3 specialists simultaneously)

0 – 1,5 years	Home visits	319 visits 50 families
0 – 18 years	Full-time pedagogical consultations at the Foundation (one off, regular) Due to quarantine from the second half of March to June 2020, face-to-face consultations were conducted remotely.	1135 consultations
0 – 18 years	Distance pedagogical consultations (telephone, e-mail, Skype, WhatsApp, Zoom)	988 consultations
0 – 18 years	Online consultation (forum)	720 consultations 330 families
0 – 18 years	Psychological consultations (face-to-face and remote held by phone, e-mail, Skype, WhatsApp)	500 consultations
0 – 18 y.o.	Consultations with a social support specialist (face-to-face and remote held by phone, e-mail, Skype, WhatsApp)	1229 consultations

Events and festivals

69 events and festivals
1281 family took part

Lessons in Downside Up



Parent-Child Interaction Group



Adaptation group



School Preparation Group



Lesson with a speech therapist



Theater workshop for younger children



Daytime Employment Group at the Metro Career Center

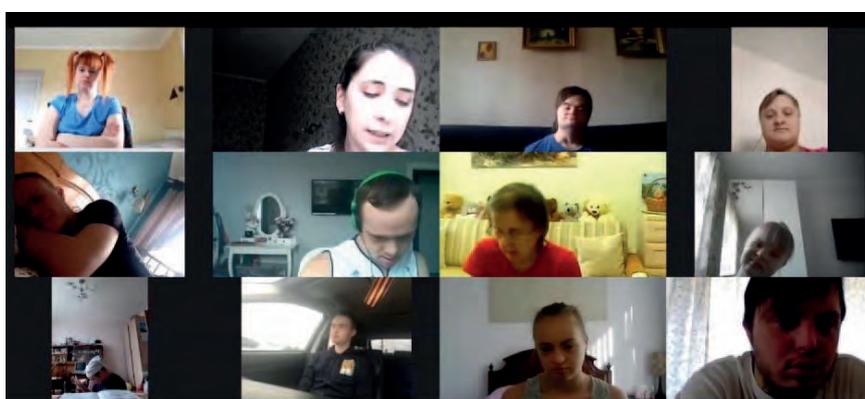
Distance learning during the pandemic



School preparation group



Teachers from the Social Adaptation Group show the fairy tale olo ok



Online reading room for teenagers and young adults



Family consultation (three specialists work simultaneously: a speech therapist, an early interventionist and a psychologist).

AWARDS RECEIVED THIS YEAR

The play "The Little Prince" by the Downside Up Theater Workshop received:

- **Diploma of the 1st degree** at the "Moscow Mosaic" Arts festival;
- **Diploma of the laureate of the 1st degree** of the IX International Competition-Festival of Children and Youth Creativity "Seven-Colour-Flower" in the category "A Petal of Hope".



Film "Jokes and Pranksters. Ku-ku, my boy!" by Downside Up Media Laboratories received:

- **Diploma of the 2nd degree** at the All-Russian festival of children's cinema and television "Veselaya Larga" in Vladivostok;
- **3rd degree diploma** at the III International Children's Film Festival "Cinema Kids" in St. Petersburg;
- **Special Jury Prize** "For Successful Film Debut" at the "Fathers and Sons" International Film Festival.

Training for specialists and parents

Since 2014, the Downside Up Education Center has been providing training and methodological support for specialists working with children with Down syndrome and their families. Parents often join the students.

In the 2019-2020 academic year:

Three full-time professional development courses for specialists:

	Number of teaching hours	Certificates of advanced training issued
1. Development of communication and speech in children with Down syndrome in early and preschool age	36	31
2. Development of speech and thinking in children with Down syndrome	42	30
3. Individual and group sessions with the family of a child with Down syndrome	42	16

17 face-to-face training events were accompanied by an **online broadcast**. There were **353** Bactive remote listeners during the broadcasts. A total of **1108** listeners registered for the online broadcast and received a video recording.

Five series of webinars for professionals, parents and non-profit organizations:

	Number of webinars	Number of active listeners	Number of registered listeners *
1. Pedagogical assistance to a baby with Down syndrome	12	411	1499
2. Methods and techniques for working with preschool children with Down syndrome and other learning disabilities.	3	629	1981
3. Managing social results for NPOs	2	16	32
4. A pilot project to form a unified regional system of interaction between executive authorities, organizations and families raising children with learning disabilities.	8	228	369
5. Accompanying a person with a learning disability through the process of employment and in the workplace	6	257	643

* - registered listeners have the opportunity to watch the video recording of the webinar.

In Addition:

- **10 separate webinars** for professionals, parents, and Non-Profit Organizations (NPOs). The webinars covered important issues on the development and education of children with Down syndrome as well as methods of working with families and children. Webinars were conducted by teachers and psychologists of Downside Up, as well as our colleagues from regional parent NPOs. **1863** listeners registered for online webinars with a total of **721** active listeners.
- **Two face-to-face, three-day courses on** managing professional activities in accordance with the social results of NPOs in Moscow. The courses were aimed at representatives of regional NPOs and parental organizations supporting children and adults with Down syndrome and their families in the regions of Russia; **32** representatives of **16** regional organizations took part in the training.
- **Two face-to-face seminars for 39 students** on the topic “Multisensory approach to teaching mathematics using the ‘NUMICON’ method. All funds received were donated to family support programs.

Other important events of the reporting year:

A new distance learning course "How to teach a child to learn and be successful? Child development in the natural environment" was developed and published on the Foundation's Internet portal in January 2020. The four-hour course is designed for a wide range of professionals working with children with special needs, as well as for parents. This course examines in detail the modern approach to child development. Unlike previous courses it uses the social model as opposed to the medical model of intervention. As of June 30, 2020, 33 people have completed the course.

The Foundation's educational activities have successfully been approved by the Moscow Department of Education and Science

The planned on-site inspection was successfully carried out by the Department of Education and Science of the city of Moscow and Downside Up's educational activities approved.

16 Downside Up specialists were trained: 14 people - in the Center of Systemic Family Therapy were instructed on the topic "DIR 101: concepts and principles of work in DIR/Floortime" (DIR is a therapeutic approach based on the diagnosis of levels of functional and emotional development of a child). Two more specialists were trained at the Center for Therapeutic Pedagogy (a regional charitable organization) in the course "Development of physical skills and creating one's borders through playing".

Online resources for families and specialists

Developing online resources in order to help more families and specialists, especially those who live far from Moscow and cannot attend face-to-face events, is a priority for Downside Up.

Access to Downside Up's online resources is through the Foundation's online portal – Downsideup.org. In April 2020, the portal was updated and as a result, is now more user friendly.

The site has a **new section "For People with Down syndrome"**.

The Foundation's Internet portal continues to be regularly updated with information and methodological materials for parents and specialists. It is necessary to register on the portal in order to access the full range of features available

In the 2019-2020 academic year, online resources included:

Distance learning: webinars, online broadcast of seminars, distance courses

For the reporting year:

- **66** webinars and online broadcasts of seminars were organized, for which **7357** listeners - parents and specialists from across Russia and abroad - registered.
- A new distance course for specialists was added.
- **38** new training activity videos available for self-study.

Professional advice on the online forum

During this year, Downside Up teachers and psychologists conducted **720** online consultations for **330** families raising children with Down syndrome from 0 to 18 years old. Approximately **10 400** monthly readers visited the advisory forum. The Downside Up Advisory Forum provides an opportunity for families to receive high-quality, professional advice from the Foundation's experts, regardless of location.

E-library

As of June 30, 2020, the electronic library contains **3148** different materials. **223** new materials were added during the year.

The library contains all the methodological manuals and journals published by Downside Up, articles by the Foundation's specialists and third-party specialists, as well as stories of parents of children with Down syndrome, photos and videos of children, news about Down syndrome from around the world and other professional and educational materials.

The electronic library is equipped with a thematic rubricator and a search system.

Обучающие видеоролики

As of June 30, 2020, the site has **141** different training videos. During the year, 79 new ones were added.

There were **10 000** monthly views.

Training videos are short and easy to understand and are developed by Downside Up specialists. They show parents of children with Down Syndrome how to structure their activities and games with their toddler step by step, and how to help their child learn the skills necessary for everyday life.

Downside Up site statistics for the reporting period:

15 628 registered users	+12 % the increase for the year
66 599 monthly average unique visitors	+112 %
4 420 daily average unique visitors	+106 %

Online correspondence "Growing Up" and "I Can Do Anything!"

32 different emails were sent to **7772** families. These emails contain important links with information on the different stages of development of a person with Down syndrome with recommendations from psychologists and teachers.

This year also saw an updated, more user-friendly newsletter.

Information Support

2618 requests for information on Downside Up services and Down syndrome generally were received.

The Downside Up website contains an online chat where questions can be posted and will be answered.

Information on Organizations

The interactive map found on our website contains information on **3693 different** organizations. During the year, **235** new organizations were added and more than **1000** contacts updated. The list of associations that accepts and provides support to children with Down syndrome and their families is constantly being updated.

Information for Families

10 596 families have their addresses listed on the interactive map with 1055 new families being added throughout the year.

The interactive family map is designed to help families become acquainted with other parents raising a child with Down syndrome in the same area. Families wishes for confidentiality are mutually agreed.

Personal Accounts on the Internet Portal

Each user has a personal account allowing him to organize selected materials, manage mail subscriptions and messages received from specialists working on the advisory forum.

Event Calendars

Electronic calendars for parents and professionals publish data on all events, activities and training programs of the Foundation, including classes for children, concerts, performances, webinars and master classes.

PARENT REVIEWS:

"Dear Downside Up employees! Although our family does not often write to you on the forum (we take a lot from the forum messages), please accept our thanks. What a terrible year it was at the beginning, when my son was born. A little later, my husband, having discovered YOUR site and organization, calmed me down a bit. We began to read the pages of your site, gradually realizing that YOU ARE GREAT! Site information, books, magazines from your center - all this is a HUGE help to all our families. Thank you, dear friends".

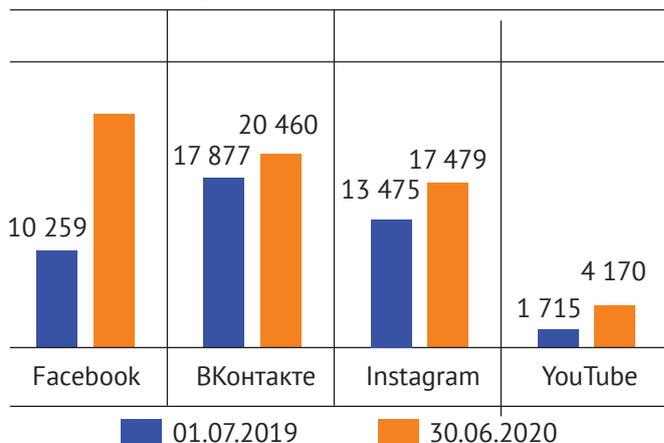
«Hello, Downside Up employees! First of all, I want to thank you for what you are! Your work is absolutely essential for our families. The literature published by your center is the most important source of information, a guide to the lives of our children. Only through it can you get adequate information about the syndrome and the development of children. For us, parents, this is very important, especially given what they tell us in maternity hospitals! I registered on your forum recently, while studying the posted information. I am very happy that through the Internet you can get not only qualified recommendations, but also simple human understanding, and most importantly support! Thank you very much!»

Information and support via social media

Much attention has been given to ensuring our social media sites deliver relevant and interesting information to our subscribers. At present over 70% of posts are aimed at developing the competencies and levels of awareness of parents on topics such as the development, upbringing and socialization of children, teenagers and adults with Down syndrome.

This year saw 610 different posts published on Downside Up social media networks. Posts are typically educational and psychological articles and videos produced by the Foundation’s specialists. During the year the number of subscribers to our sites has significantly increased; ten times more people than last year are reading our posts.

Downside Up also has a YouTube channel where all our educational videos are published. Like our newsletter our YouTube channel is constantly being improved and updated by creating playlists with the aim of making it easier for our subscribers. As a result, approximately 45 000 people a month watch video content on the Downside Up’s YouTube Channel.



December 2019 saw **Downside Up** become a finalist for the RuNet Award for “Best Facebook Community”, a well-earned victory.

As a consequence, our outreach in Facebook has increased in 40 times during the year. This was achieved with no paid for advertising.

New Educational Course “Starting to Read with a Speech Therapist”

Between February and June 2020, a series of webinars “Starting to Read with a Speech Therapist” was posted on the Foundation’s YouTube channel. Developed by Downside Up’s speech therapist Irina Anatolyevna Panfilova, these webinars were designed for parents of children with Down syndrome. It soon became evident however that they were also of great value to professionals working with children with Down syndrome. They received a total number of 15 721 views.

The webinars are systematic and cumulative acquainting the child and his parents with the four stages of learning to read (“Acquaintance with letters”, “Global reading”, “Syllable-by-Syllable reading” and “Analytical-synthetical reading”). Each lesson consists of a video presentation followed by exercises.

The posting of these materials was accompanied by 6 liveroadcasts from the author on our social media platforms. A total of 700 000 views were registered. For many parents, these videos are the only opportunity they have to receive expert support in teaching their child to read. Consequently, they are in high demand both in Russia and abroad.

As a result, many children with Down syndrome have learned to read if they were not reading before or have significantly improved their reading skills. Moreover, parents and specialists have learned how to get the best results.

Sonya’s mom review:

“Starting to read with a speech therapist” is a truly unique course, in fact, it is a step-by-step manual of teaching a child to read supported by videos for clarity. As for me, it is significant help in developing my daughter, as despite having a huge amount of information on and methods of developing children with Down syndrome, it is very difficult for a simple mother without teaching qualification to properly organize educational process of her child... My daughter loves to study, she takes the tablet and asks me to turn on this or that video. She is always smiling when she is doing exercises. And what’s even more important, such educational process has improved her speaking skills a lot. As a result of remote classes with Irina Anatolyevna, my daughter’s vocabulary has started to increase gradually, she speaks in simple sentences which earlier she could not do at all. For me as her mother this is a great success, proving that I chose the right educational method and also one more indicator of high professionalism of Irina Anatolyevna.”

Publication of methodical manuals and journals

REVIEW: “Thank you very much for the literature, there is so much interesting and useful information in it! My son is now 8 months old, and I now understand that Down syndrome is not a verdict, but an opportunity for development for both my baby and us as his parents. Your books and journals help us enormously with our daily challenges! Thank you so much!”

During the 2019-2020 academic year:

Journals published:

	Total run
Two issues of the journal for parents «Take a Step»	7500
Two issues of the journal for specialists «Down Syndrome. XXI Century»	3000

Three manuals were created by the Foundation’s specialists and published:

	Тираж
“Financial Literacy. Visual aids for education of people with mental disabilities.” T. E. Tryte, L.I. Talyzina. Artist: L.M. Chabaeva.	150
“Employment of a person with learning disability. Recommendations for social carers and NPOs employees.” N. A. Usoltseva, A.I. Burmistriva with contributions from O. O. Markova, O. E. Titaeva, T. E. Tryte.	200
Leaflet “Your child is finishing school. What next? – Recommendations for parents” Y. V. Lenteyeva, N. A. Usoltseva with contributions from O. O. Markova, O. E. Titaeva	1000

Eight manuals refined and republished:

	Total run
“Anthology for parents: Collection of articles published in the journal “Take a step” in 1997–2019“. Compiled by P.L. Zhiyanova, N.S. Groznaya	3000
“Babies with Down Syndrome: A New Parents’ Guide” by Susan J. Skallerup	3000
“A baby with Down syndrome” by P.L. Zhiyanova, E.V. Polee	3000
“Early Communication Skills for Children with Down Syndrome: A Guide for Parents and Professionals” by L. Kumin.	3000
“Gross Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals” by P.Winders	1500
“Communication Skills for Children with Down Syndrome.” By P.L. Zhiyanova	5000
“Fine Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals” by M.Bruni	1500
“Essential Motor Skills for Children with Down Syndrome” by E.V. Polee, P.L. Zhiyanova, T.N. Nechaeva	5000

Dissemination of literature during the reporting period:

- 3891 copies of books and 4299 journal issues sent to families.
- 1152 copies of books and 2495 journal issues delivered to specialists.

Analytical work

This area of work includes assessing the quality of the Foundation's programs, as well as researching the current situation regarding people living with Down syndrome in Russia. The information collected is used to improve the Foundation's work when planning new programs and to inform NGOs and the general public.

Assessment of our services from children with Down syndrome themselves.

In order for Downside Up to be successful and effective, we need constant feedback from the families and professionals we support. Systematic collection of opinions from parents and specialists with a subsequent adjustment of programs relevant to these opinions have become the norm. However to date we have not yet taken into account the opinions of children with Down syndrome themselves.

In April 2020, a new page on the Foundation's website was created "Poll results and Research" all relevant material is posted here.

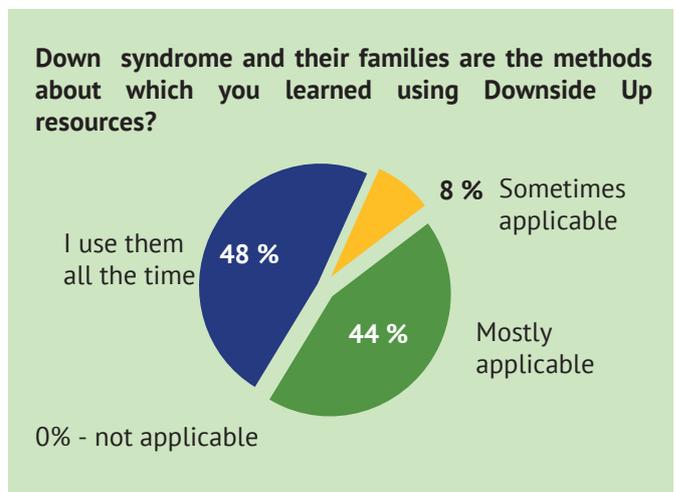
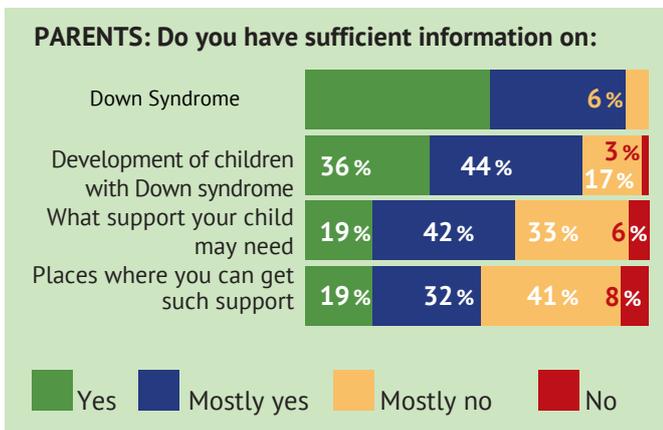
There are no specialists with experience of conducting surveys of people with learning disabilities in Russia, therefore Downside Up turned to foreign experience. Having researched the topic extensively using English-language materials we were on the brink of conducting our first surveys when the pandemic struck. As a result, our plans for this project have been postponed until next year.

In February 2020, Downside Up's 2017-2018 Annual Report was awarded **"The Golden Standard"**. This is the highest award in an all-Russian contest of public annual reports "Starting point" for socially oriented NPOs

Online surveys of parents and specialists on the social results Framework

In 2018-2019, Downside Up developed a social results framework. The framework is a ranking of results that the Foundation's work aims to achieve. These include: direct results as a consequence of conducting classes with children and parents, organizing training webinars amongst other things. By social results, we mean the impact our programs have on the society in which they operate. For example, greater tolerance and acceptance of people with Down syndrome and employment of people with Down syndrome, as well as the impact of our mission which is to improve the quality of life of children with Down syndrome. The Downside Up social results framework is presented, in an abbreviated form, on page three of this report.

In May 2020, two online surveys of parents and professionals were conducted with the aim of measuring the social outcomes and social effects of our programs. Both surveys were anonymous and executed from a database of families and professionals registered with Downside Up. **We collected 297 completed questionnaires from parents and 67 from specialists from across most of Russia.** At the time of writing the annual report, the results from the survey had not yet been analyzed however the diagrams here are an illustration of some of the responses received.



Partnership Projects

Social Results Management for NPOs supporting families with children with Down syndrome

As a winner of the Charities Aids Foundation projects contest “Strengthening NPOs” Downside Up conducted a series of important educational events for regional NPOs and parents’ associations supporting children and adults with Down syndrome and their families from across Russia. The purpose of the training was to transfer knowledge gained on the social impact of Downside Up’s activities to partnering NPOs.

The project consisted of two face-to-face three-day courses organized in Moscow and two webinars and covered various aspects of social results management. 32 representatives of 16 regional NPOs participated.

Downside Up is implementing a system of social results management and measuring efficiency of its activities. We very much hope that our partnering NPOs will apply to their day-to-day work some elements of our social results management system.

Pilot project on the creation of a unified regional system of interaction between executive authorities, organizations and families raising children with learning disabilities, including Down syndrome

The Pilot project was governed by the Fund of support to children in difficult straits. It ran from July 2019 to December 2020. The Project was implemented by the executive bodies of the following five regions: Altay Kray, Arkhangelsk, Kemerovo, Kurgan and Tambov. Downside Up’s role was as expert advisor.

An additional five regions from across the country adopted Downside Up’s protocol used to tell parents their child has Down syndrome

Using this protocol with parents is the best and most effective way of reducing the risk of abandonment to state care of a newborn baby born with Down syndrome. The Protocol that states that doctors should inform parents if they suspect their newborn baby has Down syndrome in an ethical, objective and compassionate way. The first Protocol of this kind in Russia was enacted in Sverdlovsk region in 2016. Downside Up acts as a resource center for this initiative, gathers information and provides any support that colleagues from the regions might need.

During the reporting period, our regional partnering NPOs and parental associations invested a lot of time and energy into promoting and implementing the Protocol. As a result, the decree “The improvement of medical care provided to babies born with chromosomal pathology, (Down Syndrome) “was passed in the following regions – Novgorod Region, Udmurt Republic, Krasnoyarsk Kray, Altay Kray and Kirov Region. The following NPOs operate in these five regions - Autonomous Non-Commercial Organization “House of Sun” (Velikiy Novgorod), Regional Social Movement “Sunny World” (Udmurt Republic), Krasnoyarsk Regional Non-Commercial Organization “Sun in our hearts” (Krasnoyarsk), Altay Regional Non-Commercial Organization of Parents raising children with Down syndrome “Circle of Sun” (Altay), Regional Non-Commercial Organization of parents of disabled children “The good way” (Kirov).

During the reporting period, Downside Up conducted eight webinars, in which 358 specialists from five regions participated. Downside Up’s specialists also reviewed many documents and materials provided by the five regions to the Fund of Support to Children in Difficult Straits.

PARTNERSHIP PROJECTS WITH “SYNDROME OF LOVE” FOUNDATION

In 2016, the Downside Up Charitable Foundation established Syndrome of Love Foundation. The main objectives of the Foundation are to raise funds for programs to support people with Down syndrome. During the reporting period, the Funds combined their efforts in the implementation of three projects.

Career guidance and employment

Classes and internships. Throughout the school year, Downside Up hosted weekly classes for 25 teenagers and young adults along with seven career advisory excursions to different settings. There were many successes including a two-month internship as an assistant cook in the kitchen of the Russian State Social University (RSSU) student canteen, as well as two two-month internships at ROSBANK and Rocketbank, as assistant office Manager. Downside Up specialists accompanied the trainees to their places of work.

Development of informational and methodological materials and development of online resources. During the reporting period the following were developed:

- Methodological guide "Employment of a Person with a Learning Disability" for employment agencies, NPOs and company employees. 200 copies distributed.
- Booklet for parents of children with Down syndrome "Your Child Graduated from School. What's Next?" 1000 copies to be distributed.
- Booklet for people with Down syndrome "Who Do You Want to Be? I Choose a Profession." 1000 copies will be distributed.
- Video "Where and for Whom People with Down Syndrome can Work".

Online pages on career guidance and employment have been created for parents of teenagers and young people with Down syndrome.

A series of webinars, a round table and courses aimed at companies wishing to employ a person with Down syndrome. April 2020 saw the Foundations jointly hold a series of six webinars "Supporting People with Learning Disabilities in the Workplace". In May - a round table intitled "More Than Work.

Employment of people with Learning Disabilities in Russia". 93 specialists from 41 organizations participated in the webinars, and 20 specialists from state employment services, NPOs and companies participated in the round table. Also, during the reporting period, the specialists from both Downside Up and Syndrome of Love conducted group and individual trainings for more than 100 employees from four different companies: ROSBANK, Rocketbank, Decathlon and Mosgortour.

Football

Football clubs for children with Down syndrome ran in 12 regions of Russia. In total approximately 600 lessons were held for 150 children with Down syndrome. Outside of Moscow, the project was implemented by regional NPOs and partners.

In November 2019, the first **Moscow mini-football competition was held for people with Down syndrome** in Russia. 13 national teams from 10 different cities participated. Competitions such as this help raise the level of Russian football for people with Down syndrome and, in the long term, make it possible for the players to compete internationally. Moreover, competitions like this draw public attention to the challenges people with Down syndrome face in the field of sports, along with their achievements. The competition was covered in the media by amongst others: Match.TV, Komsomolskaya Pravda, the sports Internet portal Championship, "Social Navigator" of RIA Novosti.

Volunteering

During the reporting period Downside Up specialists trained 28 new volunteers and seven volunteer travel buddies. They conducted three online awareness lessons on how to interact with a classmate with Down syndrome in three schools. A total of 60 school children and 48 students took part. Downside Up psychologists developed a diagnostic questionnaire for potential volunteer travel buddies and conducted 20 interviews. As a result, 10 new volunteers began supporting 10 young people with Down syndrome enabling them to regularly be accompanied to classes and events held by the Funds.

Working with media

During the reporting period

- **107** articles and messages were published in media covering the Foundation's activities, including:
- **5** TV shows on federal TV channels (First Channel, OTR, RTVI etc.)
- **102** publications in hard copy and online ("Komsomolskaya Pravda", "Mercy", "Orthodoxy and the world". "Moscow Komsomolets", "Evening Moscow" etc.)



28.10.2019

«The thought flashed through my mind - to take another child»: stories of parents of children with Down syndrome

«Tatiana Nechaeva, Downside Up Family Support Center Director:
 - Children with Down syndrome develop and reach their full potential if they are raised from birth in a loving and caring family. They have strengths and weaknesses like all children. We can and should develop their strengths in order to support their development. Early intervention and support to parents from our specialists will maximize the progress of the child and create the best conditions in which to thrive.

ТАКИЕ ДЕЛА

07.02.2020

Get out of the shadows. Report, photo and interview with Svetlana Nagaeva

«Sveta cried for several hours, and then at night wrote to Downside Up, a center that supports families raising children with Down syndrome. Almost immediately the psychologist replied and remained in touch for that first difficult week. <...> Looking at his mother, Timur became addicted to drawing. The important thing for him is to get on the subway, take out an album and create sketches for an hour whilst they travel to Downside Up classes. The Downside Up Family Support Center has been with them and supported them for all six years of Timur's life. »

24.01.2020

How to get a job for someone with Down syndrome with video going viral?

Downside Up Director Anna Portugalova and Downside Up Teacher Assistant Maria Nefedova appeared in the «Zadelo» TV show dedicated to raising awareness.

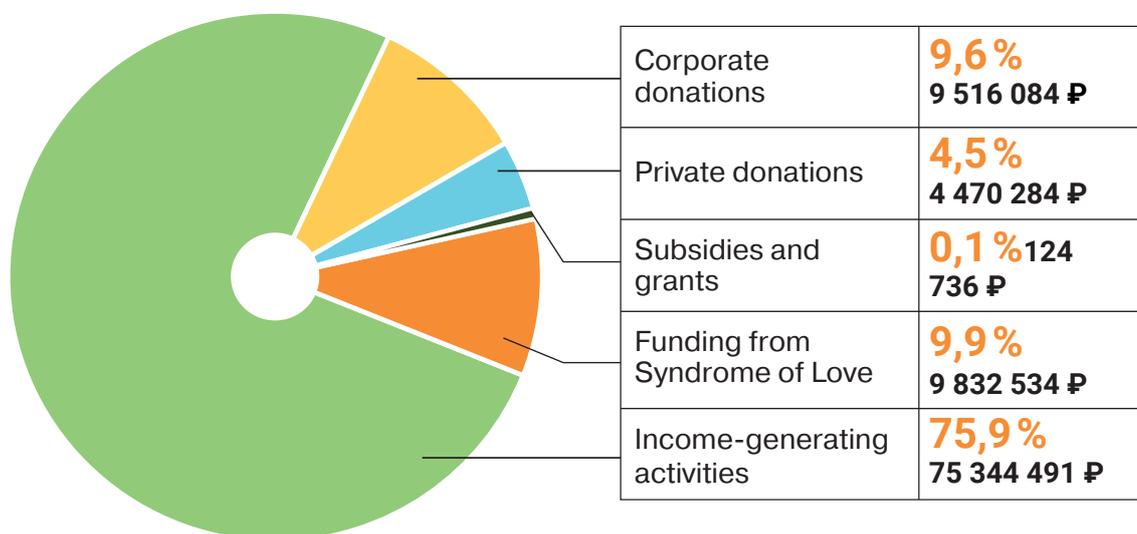


Reporting period: 1 July 2019 – 30 June 2020

	Rubles
Carry over of funds at the beginning of the reporting period	7 806 513
Income	99 288 129
Expenses	81 676 481
Remaining funds at the end of the reporting period	25 418 161

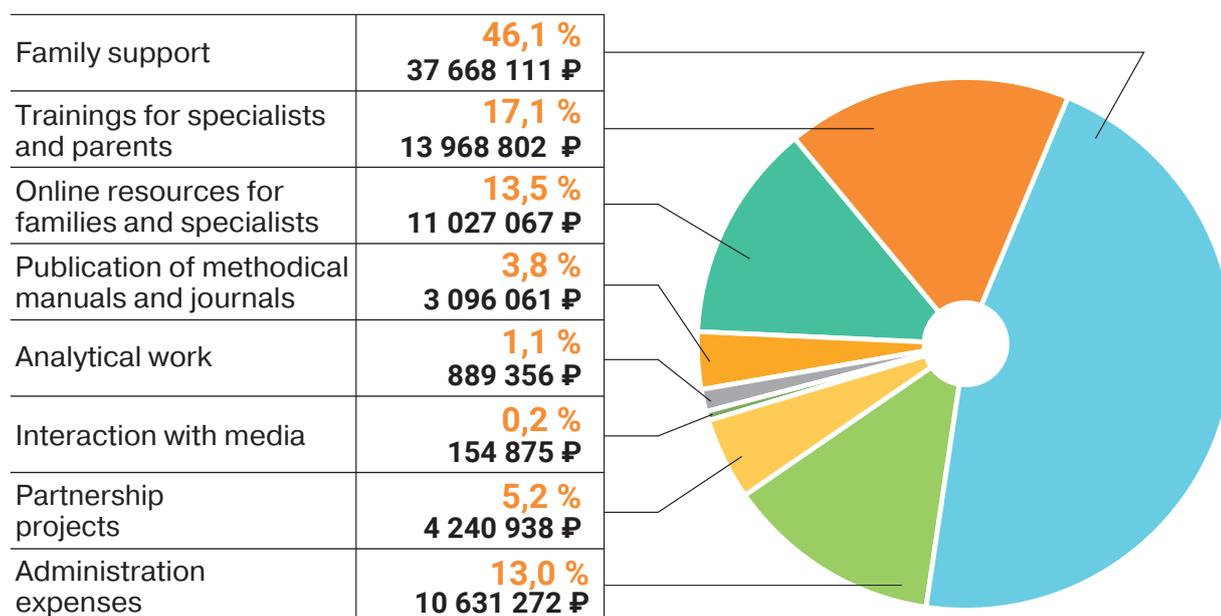
Because the Foundation received funding for projects to be implemented in the second half of the year 2020 and in 2021 there was a significant carry over of money from the previous reporting period.

Funding resources



Income-generating activities are fee paying webinars using the Numicon method. All funds received therein are transferred to the family support programs.

Structure of expenses



Fund team

Detailed information is available on the website in the section "Management and Team"



We would like to thank everyone who supported our Foundation throughout this academic year: our donors, partners, volunteers, everyone who was with us, studied with us, came to our events and invited us to theirs, supporting us in this difficult and challenging period of lockdown! Because of you, we have been able to continue to strive for the best, to develop in new directions and to rejoice in the successes and achievements of people with Down syndrome.

How you can help us

Make a donation for Downside Up:

- Using a bank card on www.Downsideup.org (you will be redirected to the website of Syndrome of Love);
- By sending an SMS to the number 3443 with a word СИНДРОМ and donation amount;
- In cash in QIWI terminals;
- For Sberbank clients – By sending an SMS to the number 900 with a word СИНДРОМ and donation amount;
- In apps of Tinkoff bank, Sberbank and some other banks in the “Charity” chapter;
- Using a payment form in any bank (you can download a payment form from the website www.sindromlubvi.ru);
- By concluding a donations contract with Downside Up

Payment details for the remittance of your donation:

Charitable Fund "Downside Up" non-profit organization:

Current account 40703810038040100912 with "Moscow Bank of Sberbank of Russia, OJSC, Moscow

Correspondent account 30101810400000000225,

BIK 044525225 with OJSC "Sberbank of Russia", Moscow
KPP 771901001

Taxpayer's Identification Number 7705159882

Payment purpose: "Charity donation (in support of the Fund's statutory objectives)"

For more details please refer to www.downsideup.org

Since May 2017, the Syndrome of Love Charitable Foundation has been attracting funds to support programs for people with Down syndrome.

Make a donation for Syndrome of Love:

- Using a bank card and Pay Pal service on the website www.sindromlubvi.ru;
- By sending an SMS to the number 3443 with a word СИНДРОМ and donation amount;
- In cash in QIWI terminals;
- For Sberbank clients – By sending an SMS to the number 900 with a word СИНДРОМ and donation amount;
- In apps of Tinkoff bank, Sberbank and some other banks in the “Charity” chapter;
- Using a payment form in any bank (you can download a payment form from the website www.sindromlubvi.ru);
- By concluding a donations contract with Syndrome of Love.

Payment details for the remittance of your donation:

"Syndrome of Love" Charitable Fund supporting people with Down syndrome

Current account 40703810738000005108 with "Moscow Bank of Sberbank of Russia

BIK 044525225

KPP 771901001

Taxpayer's Identification Number 7719449616

OGRN 1167700059262

Payment purpose: "Charity donation (in support of the Fund's statutory objectives)"

For more details please refer to www.sindromlubvi.ru



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