

# CARING AT HOME

FOR THOSE WITH EXTRA NEEDS



HOME  
RENAISSANCE  
FOUNDATION®

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# INTRODUCTION

How often we complain about how unfair life is when we really have no reason and are unable to appreciate what we have. However small the difficulties, they can seem very big to us and that makes it hard for us to feel grateful. One of the most obvious things to feel thankful for is our health.

Without a doubt, 2020 gave us a setback that made us consider this aspect. For months, the important thing was to stay home and take precautions or we ran the risk of dying or killing others. But to those who are born with some kind of disability, for those who depend on others to live, for those who due to an accident were suddenly in a body that was not their own, the pandemic offered no choices, and the home became more important than ever.

We want to dedicate this new 2021 Communication project to all those homes where people live with disabilities. We have entered these homes to learn about the difficulties that the people who inhabit them experience every day. We want to honour all those family members who give so much of themselves so that their children, their parents or their grandparents live with dignity. We want to engage with professionals working in this field on how to deal with such a situation. And of course, by making the reality of these homes and

stories visible we also want to gain the ear of our politicians and legislators. To share the message of the value of all in our society and how the care of the home is the vital factor in meeting all our needs.

Like everything in life, even the most painful or difficult, there is a good side and we are going to make it shine in this report. However, we are going to show the effort, suffering, work, pain, acceptance and adaptation, loneliness and helplessness that all these homes might experience at some time. But once again, as we always do at Home Renaissance Foundation, we are going to switch on the light and put the value on what is truly important, in this case, these PEOPLE CARING.

Mariana, Jaime, Sarah, Pablo, Roberto, Sader, Ignacio, Kara, Irene, Fernando, Benjamin, Monica, Miguel Ángel are the protagonists of this Communication Report. You will find magnificent testimonies from seven different countries, United Kingdom, Spain, Italy, Belgium, Syria, New Zealand and Argentina. Hopefully, by reading this report our eyes can be properly opened to the rich contribution those with extra needs and great hearts make to our lives and homes and our society.

# CARING AND GIVING, PERFECT BLEND





## **HAPPINESS WITH TWO CHILDREN WITH DOWN'S SYNDROME**

*by Mariana de Ugarte*



It is easy to overlook the benefits of your life training. But the gift of a good education from parents and teachers, as well as discernment in what you choose to retain and use to your advantage, is key to how well you respond when faced with unexpected and difficult situations.

It was after the delivery of my first daughter that I realised that everything that I had lived through until then, all the people who had accompanied me during my life, had given me what I needed to mature and receive my daughter, despite the initial fear after being made aware of her condition.

My name is Mariana. I am 33 years old and our two children have Down's Syndrome.

Surprisingly enough, both times we learned that our children had Trisomy 21 after birth, and both times we were extremely fortunate that our children Mariana and Jaime were born with good health and with no associated disease (something that often happens).

Obviously, the reaction was not the same - the fear we felt when Mariana was born did not manifest itself when Jaime was born, since during the two years of our first daughter's life, we had learned that having Down's Syndrome was not something bad, but quite the opposite. Therefore, I always say that **fear of the unknown must be overcome, because this is where true happiness can be found.**

I would say that to overcome that fear there are key factors:

1. How the diagnosis is transmitted to you. We had two very different experiences. In Mariana's case, the sensitivity and kindness of her paediatrician when she told us about her suspicions about Down's Syndrome, made it possible for us to assimilate the news with greater peace of mind.

2. The support network of associations and foundations. They are of great help in emotionally difficult moments, but especially important for the correct stimulation of the child in helping their development.

3. The accompaniment of other families who have gone through the same thing as you. Seeing happiness in their lives, knowing that it can be a reflection of yours, helps enormously to learn to value what you have at home.

And far from falling into naivety, we are perfectly aware that the extra chromosome that our children have means more work, effort and dedication, so that their development and learning is the best possible. We also know that visits to doctors and hospitals are and will be more frequent than in most homes, and yet I would not change a hair on my children's heads, I would not remove that extra chromosome as they would no longer be them.



**HOME, THE PLACE TO  
CARE, SHARE, TOLERATE  
AND RESPECT**

*by Baroness Hollins*



We all need our home to be a safe place, a place where we can be ourselves and where 'who we are' is accepted unconditionally. How we grow and develop will be shaped by our closeness to our 'attachment figures' - usually our parents - and to our life experiences during our developing years. Children with insecure attachments, who feel rejected, who have one or more adverse childhood experiences, are likely to have much worse mental and physical health and poorer educational attainments. This applies even more so to disabled children.

My husband and I coauthored a book (2005) in which we shared some of what we had learnt as parents of our autistic son with intellectual disabilities (ID), and some of the wisdom of 6 other families who also had children with ID.

Home is where family members learn to care and to share, to be tolerant, and to respect home as a place of safety. But home is not always a safe place, and children and young people with ID will have particular difficulties in communicating their risks and fears. Throughout most of history, people with ID have not been considered to have inner, private worlds.

In 1989 I published my first non-language dependent story (*When Dad Died*) to challenge this myth and show that even people without speech had the same need for emotional understanding and expression. I learnt the power of pictures to unlock and under-

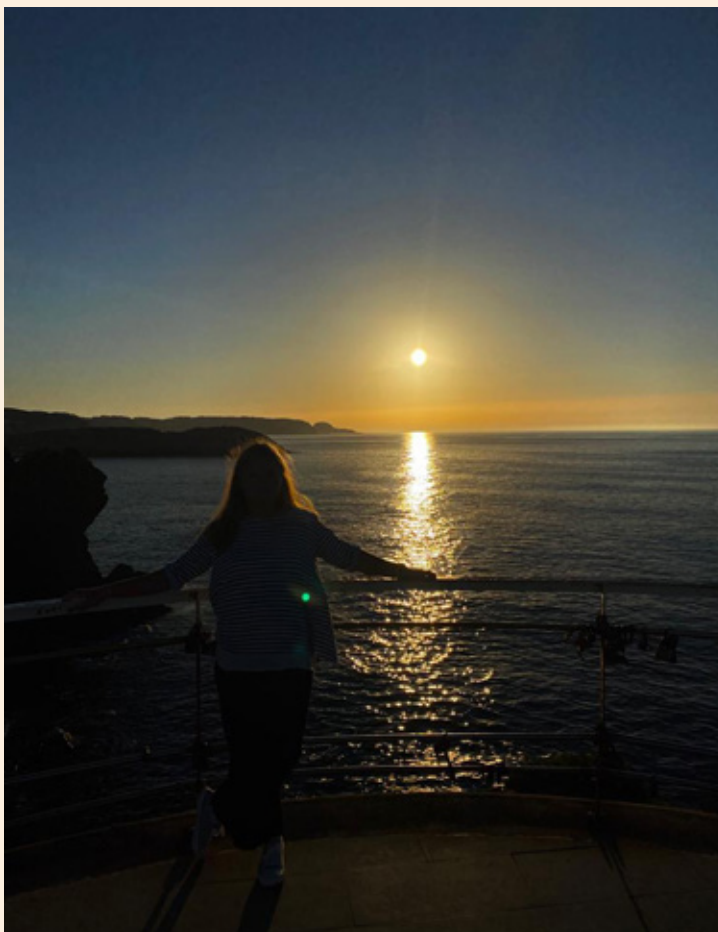
stand a person's experience from my son. I learnt the importance of watching and wondering during what sometimes seemed the 24/7 attention he demanded, alongside the competing demands of other core and extended family members. And whilst my son's care and dependency will last a lifetime, other's needs and contributions are constantly changing.

My son's presence in our family has enriched our lives both at home and in the wider world.

### References:

Hollins, S. and Hollins, M. (2005) *You and your child: making sense of learning disabilities*. London: Karnac Books

Hollins, S. and Sireling, L. (1989 - 3rd edition 2004) *When Dad Died*. London: Books Beyond Words, [www.booksbeyondwords.co.uk](http://www.booksbeyondwords.co.uk).



## **CELEBRATING THE JOY OF LIFE**

*by Rut Muñoz*

That summer changed our lives radically when you arrived at our home. It's been a few years since you became part of our family and now we couldn't imagine life without you.

In the beginning, it was challenging for everyone - adapting, overcoming the language barrier, dealing with the different experiences that you brought with you after having spent a childhood without a family... But those deprivations during your childhood - the lack of stimuli, affection, learning that a typical child enjoys, were overcome thanks to your cheerful, enthusiastic character. You became an integral part of our family in just one month, for life.

It has not been an easy ride, but together we have passed many milestones. Our home has been a source of constant learning in everyday life, in school, in laying the foundations of the values that will accompany you throughout your life. At first, we thought that we were the ones who were going to teach you everything, to provide love, affection, understanding and everything that you lacked, however, we realised that you were and are the one who gives us all that and much more. You have taught us that life is simpler than we realise and that there is no need to complicate things as long as there is an abundance of love and understanding.

Throughout the early years, the focus was on learning our language,

knowing how to express yourself well, read and write in order to lead a normal life. We have received extraordinary support from teachers and specialists, but home and teamwork have been and are, without a doubt, the engine of learning and the nerve centre of our lives.

We are proud of you, of how well you have adapted to your new life and the work that we have achieved all together. You have not only given much to us as your parents, but also passed on your joyful spirit to your sisters and nephew and instilled in them the desire to keep improving.

Our home is the hub where we support each other, a refuge when things do not go quite according to plan and where we celebrate the joy of life.



## **IGNACIO'S MIRACLE**

*by Horacio Joffre Galibert*

My name is Horacio Joffre Galibert\*. I have 8 children. In 1982 the arrival of Ignacio (our third son) was a great celebration. Ignacio was a beautiful baby, and he was very quiet to the point of being almost inaudible, and the sound of his crying was curiously distressing. When Ignacio reached the age of three months, the pediatrician who examined him found he was perfectly healthy and assured us: "No child is less equal to another, your child is perfect".

Ignacio had a blank stare and when we tried to play with him, he did not respond, almost as though he belonged to another universe, locked in a somewhat mysterious space we couldn't access. As time passed the characteristics became more and more evident. A long and painful journey began that led me to discover little by little the implications of Ignacio's "enigmas".

At five months old, Ignacio did not have strong muscle tone, and was almost like jelly when we tried to sit him up. Then it became apparent that Ignacio was leaning his head on his right shoulder, and he could barely smile, could not sit still, and we had to carry him permanently in our arms. The neurologist advised us to visit a specialist in developmental problems. It was a long journey with multiple assessments, until finally we received the diagnosis: "Ignacio has a profound developmental disorder of autistic type."

After receiving this news began the painful period of mourning and acceptance. We are a large family, but despite this, the focus of everyone's attention was still on Ignacio. The financial difficulties of coping with this complex disability grew daily. The National Health System did not cover specialized care of this nature and there was no financial support or grants for such needs.

Ignacio went through a stage of acute hyperkinesia, self-aggression, with his stronger physique more resistant to blows. But the family did not lose heart, and every night we gathered all the boys to pray together to receive renewed strength and to face the new day. His bouts of self-aggression continued to increase. He was beginning to bang his head against the wall, doors, tables, gashing his forehead or cutting his scalp.

We resorted to recreation, sports, art and music, and this became a healing therapy for the entire family and our group of friends.

Years have passed and every member of this household is now engaged in some way in enhancing the well-being of people with autism, either as carers, teachers or simply by showing affection. Our home life was the motivator for the course taken in their lives and their life projects.

In this context, a family movement was created; it began in 1983 at the initiative of pioneering parents who, after several failures, managed to for-

mally consolidate on August 25, 1994 as the Argentine Association of Autistic Parents -APAdA-.

Today, thanks to APAdA, professionals and institutions that implemented resources, Ignacio and thousands of other autistic people have the possibility of exercising their rights and directing their lives. Ignacio currently lives in the San Ignacio Community, a home-respite centre that is run by Augusto, the fourth of his eight siblings. We support places where they can develop in the most independent and autonomous way possible, with socialization and inclusion to achieve the human right to happiness.

Ignacio's miracle is that it's now understood that he has his own way of being and living in this world. This is no better nor worse than ours.

At times we have felt anger, at others' impotence, sadness or uneasiness. But at the same time, being with Ignacio has taught us to exercise patience, to acquire strength, to discover that we can be courageous.

Whenever we saw him smile, we learned to accept it as a gift from God, and to find in each gesture a sign of hope that has helped us to continue always going forward.

The miracle of Ignacio, finally, takes place also in the hearts of people who put effort, desire, and love to achieve it.

\*Horacio Joffre Galibert is the Founder and President-General Director of APAdA, Argentine Association of Parents of People with Autism. His son, Ignacio, who is 38 years old, has severe autism. Horacio Joffre Galibert has been working for over 30 years, promoting public legislation for people with autism, and other disabilities, and informing their parents about the rights of their children, enhancing the wellbeing of people with ASD (Autism Spectrum Disorder). APAdA has also been promoting the autonomy at work for adults with ASD, creating more job positions while improving their working conditions.





## **TOGETHER WE TAKE CARE**

*by Adriana Espina*

I am Adriana Espina, I am 11 years old, and I am the third of five siblings. Also, we have a dog, Yuma, who we adopted three years ago because she helped Fernando a lot with his development.

We now live in Santander, but Fer was born when we lived in the United States. There he was diagnosed with autism when he was one and a half years old. I remember that he ran around the house a lot, he spoke a Martian-like language and turned many times on himself, like a spinning top. The only thing he paid more attention to was the kids' songs that we played for him on TV.

He used to bite us and together, we tried to stop him, but when he started with the therapies going from one State to another with my mother, a therapist explained to us that we had to say to him: "Fernando, stop!" and in general he obeyed older people, Lola (aged 9) and myself, but not every time.

After several years of therapy, Fernando has changed a lot so that now he is not at all aggressive - although you always have to be careful not to touch his toys. His Lego toys are his greatest treasure... and like all children he also enjoys others' toys, especially his little brother Jorge's (aged two), with whom he has a special relationship. They love each other very much but they spend a lot of the day wrestling with one other.

Fernando loves babies, and when

we are out, he goes up to them in the street, simply to see and touch them. He is also very fond of dogs but going outside was not always easy. That is why Yuma came into our home. It was impossible to go out for a walk and for Fernando not to try to run away and escape. But it works well with both fastened to a harness as Yuma is a heavy dog so when she sits down it is virtually impossible for Fer to budge her. Little by little, Fer learnt not to attempt to run away.

Fer's favourite food is Cuban rice, but it was also a challenge for him to eat well, like others with his condition. In the US it took three therapists to come to our house to teach him how to eat. And every member of the family had a role to play to help. They asked me to clap a lot and be happy, congratulating Fer every time they gave him a spoonful, so he understood that eating was good and that he was doing great.

When we once visited a 'Dollar Store', a man helped us carry the goods to the car. He asked me how old I was and Fernando's age. I told him that Fer was two and that he had autism. Surprised, he told us that he, too, was autistic and that he had gone to college, although at times he took to running through the halls.

When we arrived in Spain, I was in fourth grade and my parents persuaded Fer to go to school with us and join the class. People knew there was a boy with autism at school, but they

didn't know that he was my brother. When my classmates met Fernando, everyone wanted to take care of him. If he came to our playground, we helped him get back to his. Fer knows perfectly well how to win people over, and when he wants something from us he knows just how to get it - with his great smile and lots of affection.

# **SPECIAL HOMES: SPECIAL CARE**





## **WHILST WE WALK THE WALK**

*by Miguel Ángel Sánchez de la Nieta*

More than twelve years ago I was diagnosed with Multiple Sclerosis. For about seven years I have been travelling on an electric scooter through the streets of Madrid, a city very well designed for people like me. At home, I still move on crutches. I am a Professor at the university, in the School of Journalism and I live in a college very close to the faculty. I am five minutes away, or four and a half to be precise, if I “step” on my “motillo”, as people affectionately call my scooter.

I love university: it is an extraordinary time of life, but also a way of being. The best university student - there are good ones at my university and at my college - is a rebellious young man, dissatisfied with the imperfect and mediocre, full of dreams and projects, committed to the truth, to making the world better. I am lucky to share work and home with many of them. I also share a lot of that rebellion, that nonconformity, those dreams, projects, and commitments. True: I have neither their physical energy nor their health. But they are my crutches. And I also try to support them in any way I can.

One person who has a car takes me to rehab every Wednesday. Another always goes ahead of the rest to offer me a coffee after lunch. He is not a morning person but it doesn't matter, as at breakfast there are already early risers ready to bring me the croissant or make some toast. There is another who is like my Guardian Angel: he always appears when there is furniture obstructing my path. They always tell me to ask for what-

ever I need: at first it was hard, but they convinced me. “Give us the opportunity to serve, to be generous,” they said and with that, I surrendered.

Apart from thanking, what else can I do? Thank God, I have no other problems at the moment: my cognitive abilities are fine. I can read, study, keep up to date. I like to be in the loop of social, cultural and the latest trends in the news... And I love talking to them (well, more listening). And I dream of being able to inspire, encourage, invite, and excite these young university students who are the future of this world, which so full of challenges.

Whilst we walk the walk, never better said.





## **CHILDREN ARE SUCH TRUE EXAMPLES OF ADAPTABILITY**

*by Annick Lievens*

I am Annick Lievens, an educator specialising in residential accommodation at the IRAHM in Brussels, which is the Royal Reception Institute for children with motor disabilities. Day-to-day life here is not easy since we face very tough life situations, and the pandemic has increased these difficulties. Since the beginning of coronavirus, we have taken care of 36 young people 24 hours a day, facing new complications and adapting daily to new health measures.

The feeling we have is that the authorities here have totally abandoned the institutions for children with disabilities. Fortunately, the solidarity of the people was not lacking, and we remain united.

The ties that unite us with our young people have been further strengthened, especially with those who do not have the possibility of returning to their families. Their home is the boarding school. I have the opportunity to share their daily life at the weekends, and we try to function like any other family. Each person has their own space, their habits, their needs and their peculiarities, depending on their disability.

The truth is that our role as educators acquires its full meaning. They are not alien to what we are experiencing in the pandemic and it is also a matter of concern and cause of isolation for them, which is a problem in many cases. Their activities and vis-

its have been suspended; we are the only link that connects them with the outside world.

I often wonder: How can we continue to fill the emotional void of these children, hug them, comfort them, respond to their expressions of affection, when social distancing is demanded? It is simply an impossible task. So, within the limits set, we do what we can and very often it is the children themselves who find the right balance and tell us: "Oh yes, the virus!" They are resourceful and show true adaptability.

**PABLO,  
16 YEARS OLD**

*Ulrich congenital muscular dystrophy*

My name is Pablo and I have been living in this boarding school for such a long time that it is like my second family. Since the arrival of covid, my social relationships have decreased, but I have learned that life is not always easy. I had to be admitted to hospital on several occasions and be separated from my friends and educators at IRAHM. I am in poor health and I have to be cautious. What saddened me most about this pandemic is having to limit my contact with people in the outside world. The support of my educators and the presence of my friends help me to cope and hope that life will soon be as before.

**SARAH,  
11 YEARS OLD**

*Cerebral Palsy*

My name is Sarah and it seems to me that it is a very sad time for us because our activities are limited. I'm a Scout and I used to make plans outside of boarding school, I also rode horses. Since this virus has arrived, all this has completely stopped. What helped me a lot was being able to go to school and see my friends. I am living through the situation quite well and I have already had 6 tests. My only wish is for this virus to go away once and for all.



## **MY FATHER HAS DOWN'S SYNDROME...**

*by Sader Issa*

I am studying dentistry and love sporting activities, especially swimming and bodybuilding. I'm a pretty regular guy who enjoys watching movies and spending time with my friends. I currently live at home with my parents in Syria. My father was born with Down's Syndrome and his four brothers and three sisters have always loved him and treated him with the utmost respect. My mother and father were introduced through family and I think it was pretty much love at first sight!

Everybody admires my father. He works hard in a wheat factory where he has been employed for the past 25 years, 6 days a week. In the winter, he oversees the sale of the summer produce and in the summer, he works on a machine that grinds the wheat. We are a pretty regular family. My mother runs the home and works hard while my father is out at work, and I focus on my studies.

We have a great father and son relationship – he is like a best friend and brother as well as being my father. I totally appreciate everything that he has done for me. My father loves and supports all that I do, unconditionally.

My father enjoys watching Syrian TV shows, visiting relatives, and drinking coffee with neighbours. Having a father with Down's Syndrome has impacted my relationships for the better. Many people look up to our family because of all that my father has achieved.

As a child who grew up with a father with Down's Syndrome, I know exactly how pure-hearted and loving they are but also that they have ambition, deserve a decent life and do not deserve to be aborted. What makes me most proud of my father is that although a lot of people thought that what he was trying to do was impossible, he did not pay attention to them and worked hard to earn money for his family so that I could go to university and study to become a dentist.

Many people mistakenly think that a person with Down's Syndrome is not able to live a normal life, that they are unable to get married or have kids – it may be rare (there are currently 3 documented cases of a male with Down's Syndrome having a child though there may be many undocumented cases), but my father is an example that it is possible!

I believe that every single person in this world deserves to be loved and respected, and that it should be acknowledged that people with Down's Syndrome or with other disabilities are able to achieve a lot more than many assume.

# **CARING FROM A PROFESSIONAL PERSPECTIVE**







## **CARE AND THE HOME ENVIRONMENT**

*by Víctor Rodríguez*

Autism Spectrum Disorder (ASD) is the most common diagnosis of developmental difficulties in children. Currently, the United States Centre for Disease Control and Prevention estimates that 1 in 59 children meets clinical criteria consistent with ASD.

Today, protocols with empirical evidence for the treatment of Autism yield very solid conclusions. Treatment should be intensive, between 20 and 40 hours of intervention a week. The initiation must be early and individualized, both in terms of context and family training. The focus should be on Applied Behaviour Analysis (ABA), that is, on the effective teaching of skills, from the motivation and enjoyment of the child.

I am Víctor Rodríguez, Psychologist and Speech therapist, and graduated from the Ramón Llull University. I specialised in Applied Behavioural Analysis in Barcelona and Minneapolis with Dr. Eric Larsson. For more than 20 years, I have been treating young children within ASD and their families.

Autism is one of the most invasive developmental disorders in a child's life and with the greatest impact on a child's vital development. Nothing or very little is easy when the word "autism" is involved. But because it is not easy, it does not mean that accompanying these people in their processes is not completely and radically wonderful and fascinating.

If you asked me what the factor with the greatest impact on the treatment

and prognosis of a young child with ASD is, without any doubt, I would say the training of their parents and the preservation of their immediate environment. It is not possible to separate the treatment that people with a diagnosis of autism require from the support of the most significant people, their environment and their home. It would be like playing football without a ball or a birthday cake without candles.

For example, in the development of a typical child (without difficulties), the preservation of the environment is the trigger for greater learning and stability. The healthy environment allows us to increase the behavioural health of any person and, from that perspective, it is from where the child becomes the protagonist of their development and their life.

In the case of people with ASD, regardless of the pathology, beyond the disorder and its conditioning factors, two key elements also prevail at the clinical level: the need to support the child in a healthy home and the need to train their caregivers. Both aspects allow: accelerating the subject's learning, preventing the development of inappropriate or unhealthy behavioural habits, providing sustainability to skills and empowering the environment to increase the quality of life of all the people involved.

So yes, home and family are truly important in these cases.



## **GREAT BABIES, INCREDIBLE FAMILIES**

*by Belén Concejero*

Hello, my name is Belén Concejero and I am a Child Physiotherapist and Osteopath.

I feel a true vocation for my profession. I love welcoming families because even if they arrive scared or worried, they always leave with a smile. There is no "little one" that can resist us.

With the patient you see in the photo, Benjamin, we do neurological physiotherapy, a specialisation that treats and accompanies children with Down's Syndrome or children who have a developmental disorder or are at risk of suffering from one. They are generally genetic, neuromuscular problems or with some damage to the nervous system.

His sessions right now are focused on sensitive stimulation, infant massage (which has borne so much fruit in kids with Down's), visual therapy, work against gravity, head control in unstable situations, vestibular adaptation, reach ... and we are at full capacity with his family.

Because what is clear is that families have to get involved in therapies. It is what is known as the family-centred model, and we have to teach them techniques that can continue at home so that the stimulation is continuous, and everything has an impact on the good of the little one.

Every day I open the door of the office thinking that whoever chooses a job that they love, does not feel 'at work' any day of their lives.

And although at Little by Little we cannot say that we are on holiday, receiving people is a real joy and we bond well with our patients and their families.

Work in early care is essential because brain neurodevelopment and neuroplasticity play in our favour. In the first 3 years of life, stimulation and play are very important. The diagnosis is not the end, merely the beginning of a journey we make together - with many activities to look forward to, including rolling on the ground, ascending climbing walls and enjoying the therapeutic swing.

# TAKING CARE BY GIVING VISIBILITY





## **A YOUTUBE CHANNEL TO PROMOTE DEAF AWARENESS**

*by Kara Gillespie*



Hi, my name is Kara Gillespie. I'm 15 years old and I am profoundly deaf. I wear 2 Cochlear implants and I also have autism. I was born at 26 weeks, so I had a lot of health problems.

I was kept in the hospital for over 5 months, till I was healthy enough to get home to my family. I was only 2 lb when I was born, weighing the same as a bag of sugar and I was the size of my Dad's hand.

I was born deaf, but my family didn't find out until I was one and a half years old. So I was fitted with hearing aids when I was two and then the doctors told my family that I would be a good candidate for cochlear implants.

I had my first cochlear implant fitted on the right side a year later and had operation on the left when I was four. My mum, dad and sister are all hearing, so I am the only deaf person in my family.

When I was younger, I used to be embarrassed to be deaf and having autism. So, my family told me that I should be so proud of myself. That's when I decided to start a YouTube channel to promote deaf awareness. The first video I made was so popular that I decided to make many more videos about deaf awareness. I have had people contacting me from all over the world.

The National Deaf Children's Society asked me to become a Young Campaigner for them. I recently campaigned for clear face masks to help

deaf people during this pandemic.

I love being the way I am and I will always campaign to help deaf people in the future.



## **ART IS AN ACT OF LOVE**

*by Stefano Cipani*

My name is Stefano Cipani and I'm the director of "My brother chases dinosaurs".

I've been a film lover as long as I can remember and my dream has always been to create interesting characters. I grew up with all kinds of films, from westerns to horror. I love those films where you can feel the touch of a sensitive artist. Art is an act of love. We make art because we want to be understood and we want to ask questions about those topics or arguments we care about.

Since the beginning of this adventure, I have been caught up in the relevance of this film, because it is based on a true and momentous story. This is why I decided to be involved in the project. And that's why all the people involved, from the Producer Paco to Rossy De Palma and Alessandro Gassman, felt enriched and truly moved by the Mazzariol Family.

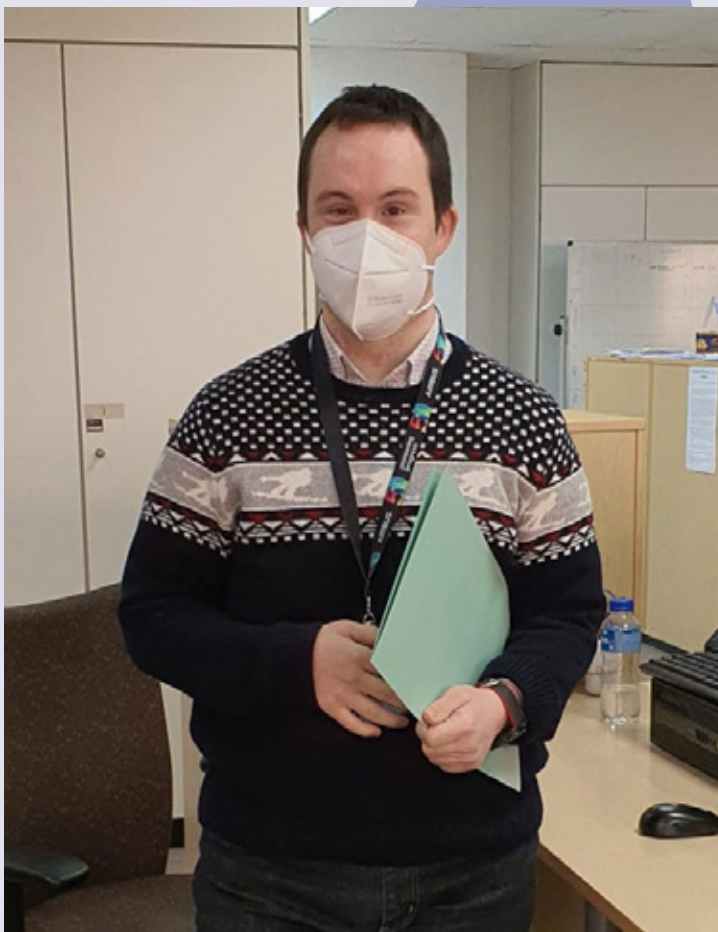
And that is the secret. The Family. It does not matter how strange and outlandish your family is as long as it is strong and united. The family must be together, democratic and open. We, the film crew, fell in love with Gio and we all moved in the same direction: the direction of love.

Working with Lorenzo was great, and also with all the other kids involved. Lorenzo (who has Down's Syndrome) is a talented actor and is very aware of what acting means. We treated him the same as all the other kids and he behaved just like the

others: he worked without complaining, and sometimes he was tired, but he never let go of his responsibilities. He never caused any problem. He was a true professional and he delivered. I think this is the real message of the film. His family has been deeply moved by the experience of having a "child actor" among them. He has gained self-esteem, and his parents, ironically, say that they now have what they like to call a beautiful "family video."

I think I was very fortunate in finding such an original and inspirational story. The cinema should focus on these subjects, with the big challenge of how to entertain the audience and tell the story with powerful imagery. The narrative needs to be strong and true. Unfortunately, it is hard to find one as remarkable as this one: a teenager dealing with something difficult to understand. That is what the film is about for me.

Somehow, our society is still a "teenager"- in denial about what it cannot understand.



**WHAT DO I DO?  
I AM IN THE BUSINESS  
OF MAKING PLANES**

*by Roberto Guerra Álvarez*

I am Roberto Guerra Álvarez, I am 36 years old and I started working on January 3, 2006, at the AIRBUS factory in Getafe. AIRBUS is an international company that designs and manufactures planes.

I still remember my first day, and it's been 15 years now. It was a cold morning and my mentor was waiting for me as I stepped off the bus to show me the way to building A-4, where she joined me to work as an office assistant at the Archive. There I devoted my time to computerised microfiche, filing and helping in the purchasing department doing photocopying and scanning, etc.

I loved seeing the planes take off and I was very impressed to watch the Beluga fly for the first time. Have you heard of it? The gargantuan Beluga cargo plane, which bears a striking resemblance to a whale, can transport huge assembly parts.

After a while, I moved on. I was informed about a department change. I had to leave my colleagues to meet new ones and learn new tasks in Customer service. I became an expert at filing: I classified, ordered and collated the invoices issued by my colleagues so that everything was in order. It took me a while to learn all the tasks, but with a lot of effort and the support of my mentor, I managed to master the job and feel like one of the team.

The change of department and tasks was followed by a change of destination. We were transferred to the Barajas Factory and a new adventure began there.

Currently, I work in the accounts FEX department. My work has been transformed and there are no longer any paper records, as it has been computerized like everywhere else. I have also had a lot of catching up to do. I work nonstop all day long, but I love what I do, especially learning new things. I really value my work and especially my colleagues. Here I have many friends with whom I share other interests including football, video games, meals out and karaoke.

**IF I WERE  
A MINISTER  
FOR A DAY...**







## **THE SAME RIGHTS AS ANY OTHER CITIZEN**

*by Irene Sánchez*

Hello, my name is Irene Sánchez and I am very clear about what aspects of society I would change if I were a minister for a day to help people like me.

From an educational point of view, we need more after-school training programmes to better prepare ourselves for life. Currently, only private courses are offered, which are very expensive. The courses need to be more far-reaching and include personal development. For example, equipping people with the emotional skills needed to increase our self-esteem and help us tackle day-to-day issues.

During the global pandemic, access to healthcare has been more complicated. We need professionals to assist us face to face rather than just talking on the telephone. Hopefully, this will come about following the vaccines.

The issue of housing is a challenge for us. We would like to live an independent life, but getting a home is not easy. More sheltered accommodation would be necessary. We need the support of institutions, and personal assistants who work with us, teaching us how to be autonomous, how to handle money, use public transport and carry out the work of the home.

Employment is a very important issue. With the pandemic, many of us have lost our jobs and others find it difficult to 'telecommute' from home.

We would need specific training for this in order to carry out our various jobs.

And lastly but not least, people with Down's Syndrome should have the same rights as any other citizen. We want to be able to participate in all aspects of society, - working and helping others and also having fun. And gain everyone's respect.



## **LET'S EDUCATE IN VALUES AND LOVE OUR PARTICULARITY**

*by Monica Reading*

My name is Monica, I am 42 years old, I live in New Zealand and I have impaired hearing.

My mother is deaf, and so are her brothers. My father is deaf and mute. They are from a generation where there were no cochlear implants, and they were never able to be fitted with a hearing device. Although we have a genetic tendency to hearing loss in my family, my son was born without any problems.

Undoubtedly, my life would have been very different if my parents had been able to hear and if I had been born with better hearing. I am not complaining, throughout my life I have been acquiring skills and abilities to try to lead a normal life, but it has not been easy. Sign language is foreign to most people and I live in a different country to where I grew up, as I previously lived in London. It has been more complicated since the pandemic, as mask wearing has prevented us from being able to lip read.

My childhood and adolescence were hard. I would not say that I was not happy, but we lacked a lot of information, so we could never feel free and equal. Perhaps now with the internet and technological advances, everything has changed for the better and families with children who are deaf have more opportunities than we had. My sister and I were always made to feel at school that our family was different.

My hearing loss has placed limitations on what I can achieve as it has been difficult for me to find a job and make friends. I am an open and sociable person but meeting in bars or restaurants is a complication for me since with background noise I cannot understand conversations and I come across as disinterested, shy and introverted, whereas in reality I simply can't participate because I can't hear.

I think there is very little awareness regarding people who are deaf. An everyday occurrence that should be straightforward, ends up being complicated. For example, earlier today I went to the ENT to have my hearing assessed by a specialist but when he spoke to me, he didn't look me in the face. He was very nice but not very empathetic.

This is often the norm for us in society. I feel a certain discrimination, especially when you see other causes awarded vast amounts of money with huge advertising campaigns and visibility in the media, yet the cause of the deaf and mute appears to pass unnoticed. How is it possible that sign language, which is so vital for communication for so many people throughout the world, could have been rejected as an official language?

I am clear that if I were a minister for a day, I would work to make society more inclusive, and genuinely so. No one would feel an outsider, with equal access for all, so that a disability would not be an excuse for inequality.

People with disabilities generally have access to jobs that are low-skilled, which seems grossly unfair. Why can't a deaf person be an engineer or a doctor or a pharmacist? It would mean investing in subtitles, visual alarms, installing magnetic loops in public places, and providing free public interpreters. Free hearing aids should be available to everyone who needs them and educational programmes offered to families to help them value and love their particularity. Because self-love begins at home and if you don't value yourself, no one will. So, let's fight for what we dream of and don't let anyone tell us we can't. Seeing those you love thriving also helps you feel happy.

We have to love people as they are, however, different or difficult they are - arriving late, chewing gum noisily or constantly complaining. No-one is perfect.

# EPILOGUE

Lucy Hawking is a journalist, novelist, educator and philanthropist. She is the daughter of the world-renowned British theoretical physicist Stephen Hawking and writer Jane Wilde Hawking.

Hawking is vice president of the National Star College, an institution dedicated to allowing people with disabilities to realise their potential through personalised learning, transition and lifestyle services, a foundation which provides care and education for young adults with complex and multiple disabilities. She is also a trustee of the Autism Research Trust.

She has a son, William, (24), who was diagnosed with autism. He has been an inspiration to her in her support for people on the autistic spectrum. And as a young adult she was a carer for her father as his health declined due to motor neurone disease.

She also wanted to participate in this project and her message is:

"Care in the Home is an essential service on which many families rely to keep their loved ones safe and healthy. It takes great compassion, trust and dedication on both sides to establish a harmonious and successful relationship.

Good communication is key for both families and home carers to create both a stable working environment and a secure family home as is oversight, advice and monitoring by outside health and social care professionals."

Lucy Hawking

*President of Stephen Hawking Foundation*



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