The hopes and dreams of children with disabilities
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Cover photo: Drawing by Fatjona from Albania, depicting what a full life means to her. With her brother’s help, she painted their home, flowers and each other.
Preface

This is a collection of stories from children with disabilities around the globe, sharing their experiences, their relationships with others, their fears and hurts, and their hopes and dreams. These stories are not about World Vision’s contribution. Rather, they illustrate that children with disabilities have dreams and aspirations, just as children without disabilities do. They also reveal the daily struggles and life challenges children with disabilities face – such as the negative attitudes often prevalent in society, issues related to self-image, and inaccessibility of facilities, roads, transportation, communication or other social systems and services. Some of these children are embraced by their families, while others feel rejected or were even abandoned. Yet the resilience displayed by all of these children is inspiring. They are a great testimony to John 9:3 ‘…but this happened so that the works of God might be displayed in him’ (NIV).

Readers will find the children are determined and hopeful for their future, and it is often their parents’ fear that is most striking. When children with disabilities pursue their hopes and dreams, their parents recognise the extraordinary strength that will be required to face the many obstacles.

Some of the stories were told in the children’s own words, while others were written by interviewers. Through these stories, we hope readers are challenged and inspired to work within their spheres of influence to ensure children – and indeed all people – with disabilities are included in all aspects of society.

Thank you to the World Vision communicators and disability advisors who helped to gather these stories and photos.
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Introduction

There has been a powerful and long-awaited change in the understanding of disability over the past decade. The conventional understanding that persons with disabilities cannot fully participate in society because of their disabilities is no longer accurate, appropriate or welcome.

Thanks to the disability movement, led by persons with disabilities and advocates, and the effects of the UN Convention on the Rights of Persons with Disabilities (UN CRPD), the world today understands that barriers in society can ‘dis-able’ a person.

These barriers may come in the form of stigma, myths or negative attitudes towards persons with disabilities. Or the barriers could be a result of inaccessible infrastructure, social systems or services such as transportation, education, primary health or communications, or employment opportunities. Barriers that set participation limitations can also be assumptions made by people without disabilities (including professionals) regarding what a person with a disability can or cannot do. Persons with disabilities need more than medical or rehabilitation support if they are to fully participate in society in an equal and meaningful way.

We want to see children with disabilities thriving in safe environments, learning in schools, enjoying good health, and becoming prepared for life. We want to see the same rights that are guaranteed to all children in the UN Convention on the Rights of the Child (UN CRC) also enjoyed by all children with disabilities.

The process of disability inclusion transforms everyone involved – children, youth, adults (with and without disabilities), their families, their communities and, of course, ourselves.

Being accepted, valued and celebrated as a full and equal human being is an enabling factor for a thriving life. Don’t we all remember the need to belong and be accepted as a child or teenager?

Sadly, so many children with disabilities feel isolated, are bullied, discriminated against, abandoned or even killed on the grounds of having disabilities. In the following 15 stories from children with disabilities in Africa, Asia and Eastern Europe, it’s clear that what hurts them the most is the harsh treatment and negative attitudes they are often subjected to. What they want in life is to go to school, have friends, play, succeed in what they do, contribute to their parents’ well-being and help other children in difficult situations. These are the same desires shared by all children.

Let us review and reset our expectations and aspirations for children with disabilities. It is about so much more than just concentrating on physical needs such as helping them to walk or see. By broadening the process of disability inclusion, we will celebrate a transformation of children with and without disabilities, as well as their families, their communities and ourselves.
Since the accident, my life has never been the same. I was only 8 at that time and now I am 13. During these four years I have seen more hospitals and doctors than I have seen in the movies. After the accident, I had no choice other than to drop out of school because I couldn’t speak, couldn’t walk and couldn’t even move from my bed. I had to learn for the second time everything from the beginning, like little babies do.

Everything looked impossible, until I started to speak [just some words] and move some of my limbs, like my hands. Meanwhile, I lost one school year. But I didn’t want to surrender. And so I started my second battle. After I learned to speak for the second time, I had to learn how to go in a wheelchair to the school where I used to go running. My mom, Donika, helps me get ready for school and my father brings us there by car. My mother helps me by pushing my chair and sometimes struggles to find a way through the obstacles with the chair. Once we are at the school yard, together with my friends, she has to lift my chair up the stairs that lead to my classroom. I have to ask for my friends’ help every time I want to go out of the class during the lunch break or during the physical education hour. I try to stay in the class until the lesson’s end, and my mom comes to pick me up because I can’t go home alone. There isn’t an accessible way for my chair at the school. Actually, there isn’t anywhere.

My fight to be the old Fatjona took place especially at my class. Because I was away from school for a long time, I wasn’t walking in step with my classmates. Sometimes my mouth and my hands don’t respond to what my brain tells them to do. I can’t keep notes when my teacher explains the lesson, and I can’t finish the class work at the same time as my classmates. When I am asked by the teacher to answer her questions, some of the other pupils get impatient because I need more time to answer. But my teacher is always very patient with me because she knows I have the answers but I just need time.

My parents and my brother are my biggest supporters. They are the joy of my life. My brother, Sajmir, is my idol and my model. Immediately after he finishes school he comes home, instead of playing with his friends, to help my father at the small shop we have at home, so my mom can help me do some physiotherapy exercises. He also helps me do my homework, and we spend a lot of time playing together.

I dream of being a dancer when I grow up, and I pray to God every day to help me realise my dream. Maybe for you it may seem strange that a girl like me, in a wheelchair, has a dream like this, but I have it. One of the doctors I met told me that if I want to be happy and bring back the old Fatjona I had only two choices – laughing and physiotherapy. More than anything else I want to be the same girl I used to be, and I am very close to realising this because now I have started to walk without the wheelchair, using a rolling walker. And I feel that this is only the beginning of my journey to be the same Fatjona I used to be. I will not surrender.
Disability Inclusion

Bangladesh: My dream is to be a doctor – Ritu, age 16
Interviewed by Muhamed Khaliduzzaman, WV Bangladesh

I am the first child of my parents and was born on the Bangla New Year day. We usually exchange gifts on that day. My birth can be considered as a gift from God for my parents. I am the only person among our relatives who uses a wheelchair for movement. I don’t know why God created me like this but I think God must have a plan. I believe that God gave me this lifestyle because God loves me. I am sure that I am blessed.

I have no problem to move around with my wheelchair if the places are accessible for me. My school is near to my house so I never feel any problem to go there. But travel from one place to another is quite challenging. As accessible public transport is not available here, my family usually avoids most social activities. When we do attend a gathering, people usually look at me with curious eyes. But I don’t care because I know who I am and I am not a stranger. It’s not my problem, but it is a problem of those who have difficulty accepting the diversity.

I am from a poor family with only the single income from my father’s small business. I was born with fragile legs and my parents spent a lot of money on my treatment. They did everything for me within their limits. They had only dreamed to see me standing on my legs. All of their concentration was how to make me cured and ‘normal’. After a long struggle they finally accepted the condition. I think they were not wrong, as every parent should have the same desire. But it would be fine if they were guided by the doctors properly and got the message earlier. If they had accepted this earlier, I could have started my student life two years earlier which would be good for me as well as good for them. However, this experience helped me to determine the aim of my life. My dream is to be a doctor in the future. If I can, I’ll have the opportunity to serve poor people and my parents as well. I am always sincere in my studies to achieve my desired goal. But I still believe that it depends on the decision of God.

Our school is a three-storied building and the common classroom is on the top floor. It’s sometimes really hard for me to move between these floors several times a day. I requested our teacher to shift our common classroom to the ground floor. My request was not considered because it’s not a need for many students at my school. Just imagine if there were more students like me in our schools, the response of our teachers might be different. But I never feel that I am segregated from my friends. We attend the classes and enjoy leisure time together. You may say that I can’t walk, but the reality is I can. So-called ‘normal’ people don’t need the support from their hands for walking, but everyone is somehow different. I am also different from others and I am happy with myself without any complaints to anyone.

When I was in grade four, it became difficult for my mother to carry me. She felt the necessity of a wheelchair for me but it was difficult for my family to manage the cost of the wheelchair. Once my family found a wheelchair, it was painful for me because it was for an adult. A couple of years later, World Vision helped me get a wheelchair. Some experts prepared the wheelchair according to my measurements and gave it to me. I feel comfortable with the new one and I know that it has been made only for me.

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LEARN MORE AT: http://www.wvi.org/disability
China: I can realise my dream of becoming a teacher – JunJun, age 9

Interviewed by Joy Li, WV China

When I was born, I was diagnosed with a physical disability. My limbs were of an unusual shape and weakness. They could not extend straight and were rather stiff. I had very limited motor function. Standing up properly was impossible. But all of these physical troubles were nothing compared to my inner scar. I was abandoned by my parents.

I grew up in an orphanage in Wuqing District of Tianjin. Due to my physical condition, I needed help on the most basic tasks. Whenever I wanted to go anywhere or whenever it was meal time, I needed to be taken care of. This made me unhappy. I was a burden and would always be a burden.

When I reached age 4, I was sent to a special home that accepts orphans under age 6 with physical disabilities. It had a rehabilitation centre where children like me can receive rehabilitation.

I felt like a soldier. The teachers tried different methods to train my legs. After seven or eight months I was able to stand upright. From walking without aid to climbing stairs, I was making progress by leaps and bounds, the teachers told me.

I remember one day I couldn’t contain my excitement and shouted out, ‘I can walk on my own, just like anyone else!’

When I was 6 (the normal age for children to begin school) I was confronted with another challenge. Because my hands were weak, I was unable to hold a pencil properly. The teachers experimented with different methods to help me, such as holding my hand when writing and enlarging the words so that I could practice stroke by stroke. The teachers also asked me to grab certain objects so that my fingers would gain strength. Through these targeted exercises, I finally succeeded in writing my own name. The strokes were light and the words were still somewhat unclear, but the encouragement was enormous.

I like school. There are still many difficulties – such as my slow writing speed, which hindered me from finishing exams within the stipulated time, and my inability to climb stairs, which restricted me from participating in certain subjects. I tried my best and did pretty well. Last semester, I attained 91.5 on my Chinese exams and 98 on math. Though there are still many difficulties, I tried my best and did pretty well.

I see myself as no different from other children and I believe that by studying hard I can realise my dream of becoming a teacher. As for climbing stairs, I look forward to the day when I am on the Great Wall.

Junjun can write after training.
My name is Birtukan Shalama. I am age 14 and in grade five. My mother told me that I fell on the ground while playing with my elder brother at the age of 2. My left leg became paralysed, leaving me unable to walk. My mom visited a number of health centers, even in Addis Ababa, hoping that I will be cured. But there was no way to get healed. She then brought me to a traditional healer near my village, but to no avail. I think of the tiresome days my mom spent carrying me and in search of my healing, and I sometimes think I should have died rather than let my mom suffer this way.

My mom used to train me to stand on both legs, but it didn’t work. I spent three years lying in bed, hopeless and hidden from people. I didn’t know life outside my home, what was going on, what outside even looked like. At the age of 6, I started to try to walk with a walking stick. After a number of practices, I was able to stand by myself and even walk short distances. My father, Shalama, is a poor farmer and couldn’t buy me a crutch, so I always used a stick, which wasn’t comfortable and made my hands bleed. It is difficult to put in words what I felt.

I started school at age 9. I love going to school, even though the trip is tiresome for me. Although the school is not far from home, it takes me more than an hour to reach school, while my neighbourhood friends take only 10 minutes. I can’t walk fast like my friends and I have to stop to rest. Most of the time I miss the first period. My friends don’t accompany me because I am ‘too slow’. I am very sad for not being able to do what my peers are doing. Sometimes I think that I am not loved by God, unlucky and sinful. I ask God why can’t I enjoy, laugh, run, sit, stand, play games like my friends? My heart tells me that it is because of the sin that I might have committed. My school experience is not enjoyable. The children call me ‘lame’ in the class which leaves me in tears for the whole day. I always ask myself, ‘Why didn’t they understand that I didn’t bring my paralysis on my own?’

Despite all the messes, I have a dream to be a medical doctor to help children who are outcasts like me due to disabilities. But I still have a fear that my dream may not come true because of the disability I have. Whatever may come, I am now struggling to realise my dream. When I compare my dream with my challenges, I get encouraged, enthusiastic and patient. My mom is a very good woman and always support me to make my dreams come true. I also want to be a gospel teacher. I’m a member of a choir group in my church.

My disability also causes a big challenge while using the toilet. The toilet is far from our home. Without my mother’s help, I would have fallen in the toilet many times. My mother, Tadelech, knows what I feel, what I think, what I want to do. Sometimes, she washes my hands after the toilet. God bless her! As a girl, I should have served my parents by fetching water from the water sources, but I couldn’t. It takes about two hours (round trip) for my mom to fetch water. Imagine how long it would take me! I wish I could help her.

In 2013, World Vision supported me with a supportive device for my left leg, which has improved my walking speed. I want to live a better life. I want to have accommodating toilets, schools, roads, etc., and I want to fulfil my dreams. I want my family, teachers, classmates and community to change their attitudes, be helpful, and be encouraging and supportive. I also want World Vision to teach our community to change their attitude and minimise barriers.
Ethiopia: I dream of being a medical doctor – Mubtwuha, age 14

Interviewed by Elias Ermiyas and Communications department, WV Ethiopia

Mubtwuha, 14, lives in Tulo District, 363 kilometres east of Addis Ababa.

Born with a hearing disability, Mubtwuha could not communicate a word unless she used a sign language that she developed herself through time. The communication barrier she had with her family caused a profound depression in her life. ‘It was very, very difficult for me to hear people speaking to me, and so I did not speak to people. My family did not understand what I was saying and they didn’t have the patience to listen to me. This was so irritating for me. I sometimes cried when they lacked the patience to understand me and ignored what I was trying to explain to them,’ she recalls sadly.

Mubtwuha has six siblings (two brothers and four sisters) who all went to school while she had to stay at home and support her mother with domestic chores because of her hearing impairment. ‘When my siblings went to school, I was dreaming to be like them. I was longing for the day when I was carrying a bag and going to school like them. After school, I was always amazed at how they could read and write. One day I asked my mother to send me to school so that I could read like them. My mum’s response was heart-breaking. She told me that there was no school at all for deaf people like me, adding that I had to stay at home all the time. That was the worst news for me to hear. I cried and felt desperate. Everything became dark. I lost all the dreams and hope that I had in life,’ she remembers.

Mubtwuha continued to take a great interest in school despite her disability. She was always begging her siblings to teach her reading and writing. She says, ‘They tried to teach me a little but, because they did not communicate their ideas in a way I could understand, they got bored and stopped helping me. This caused so much confusion in my life. I hated the way I was created. I was also complaining to God saying, “Why you did create me like this?”’

In a bid to give children with disabilities access to education, World Vision began implementing Inclusion For All projects in Tulo District in 2010. It constructed and furnished two blocks of classrooms and provided supporting materials including walking sticks, hearing aids, braille, etc., for the disabled children. It also trained a number of school teachers in special education as well as training the parents of children with disabilities to treat their children better and communicate with them in a more effective manner.

‘While I was in such terrible sorrow, my close friend one day came to our house and told me that World Vision was going to open a school for special needs children. That night I could not sleep at all. I rejoiced so much. Early in the morning, I woke up with my siblings and ate my breakfast. I walked to the school and registered my name at a special class,’ Mubtwuha remembers happily. ‘My mother was given training on sign language to help me to communicate. I, along with 30 other students, began attending school in 2010. I am now in grade four. Oromo language is my favourite subject. I am one of the best performing students in the class. I came third in my class,’ Mubtwuha says proudly.

Mubtwuha is very pleased with her school life. ‘The school life is very amazing. You have someone who can communicate and share your ideas. You can play, chat, run here and there. You learn a lot at school. You can read books that can tell you about your area and the world that nobody told you before. My mind is open now. I have begun to realise what is going on in the world. I have a dream to be a medical doctor.’

Mubtwuha always dreamt of going to school.

LEARN MORE AT: http://www.wvi.org/disability
Georgia: Longing for integration – Pikria, age 18

Interviewed by Ana Chkhaidze, WV Georgia

If you ask 18-year-old Pikria how it feels to live in her community, she would tell you it is ‘difficult’. She would use her hands, instead of her lips to communicate that truth.

She was just 3 years old when she was diagnosed with a hearing impairment after a neighbour noticed that she did not respond to her name. It was a shock for her family. Her mother, Maguli, still cannot talk about it without tears.

‘She was a very nervous child because she could not explain what she needed and was always crying,’ remembers Maguli.

At the age of 6, Pikria began going to school in her village. School was a painful experience for her because, she says, ‘nobody could understand me and I could not understand anything.’ It was clear for the family that Pikria could not stay in that school. Being only 6, Pikria could not communicate with her family members. She could not explain her feelings. All she could do was cry, which she did frequently.

Pikria’s mother decided to take her to Tbilisi, the capital city, so she could study in a boarding school for the deaf. ‘It was a difficult decision, as we do not have any family in Tbilisi and to let a 6-year-old child live and stay in a foreign environment was not easy,’ remembers her mother. ‘But we understood that it was the only solution. Pikria had to study and learn how to communicate.’

The first year was very difficult for Pikria. She was far from her family and still did not know sign language. ‘Until I studied sign language and started communicating, expressing my feelings, I felt very bad,’ she remembers. Right now, school is the only place where she has friends. She spends most of her time there and she feels happy.

It is still difficult for her to come to the village. She usually stays only a few days before she wants to go back to school. ‘I see that being with her peers, with friends who understand her fully, makes her feel good,’ says her mother.

Pikria has often longed to be integrated with youth outside her boarding school. But, unfortunately in many cases, it has just been a dream for her. Perhaps one of the only times when Pikria has been able to hear, understand and communicate with children her age who weren’t necessarily deaf was at World Vision’s three-day camp. Pikria went with her interpreter. She was fully involved in all the activities and training. ‘It was a very good experience and very interesting time for me,’ says Pikria.

Pikria has difficulty communicating at home. Her father does not have time to study sign language, and her mother has difficulty explaining things properly. Her siblings can communicate better, but they are often not home. Although she loves her family, Pikria calls boarding school ‘home’.

Unlike many high school students who wait with great anticipation for the end of their education, Pikria is fearful of the future. This is her last year in the boarding school. She will have to return to her community as her family does not have the ability to pay for ongoing education and living costs in the capital.

Pikria in her community.
Ghana: Returning to school with sanitation access – Abudu, age 31*

*Interviewed by Samuel Baafi, WV Ghana

‘When I was 13 years old I had exploratory surgery to find out what was wrong with my legs. After that, my ability to walk just deteriorated until I couldn’t [walk] any longer,’ shares Abudu, age 31. Abudu grew up in a time and a place where there was no consideration for people with disabilities. ‘The hardest thing about losing my ability to walk was the difficulty I had taking care of myself and accessing sanitation facilities. This went on from primary school through to secondary school,’ he recounts.

‘Imagine a person with a disability, crawling on the ground into the bushes, where other people have already defecated, to ease himself,’ he says bitterly. This was the plight of Abudu and the many others with disabilities. With no disability access to the sanitation facilities at his primary and secondary school, Abudu struggled to the point where he decided to quit school. ‘It caused a lot of health problems and, above all, it was very demeaning,’ he said.

After quitting school and returning home, he realised the situation there was also not ideal. Abudu was frustrated and searching for a permanent solution to his problems. World Vision helped connect him with a people-with-disabilities association, and he eventually formed his own association.

His association worked with a World Vision team that came to his community to assess how to improve access to sanitation for people with disabilities. ‘I was very hopeful,’ he remembers fondly.

In 2013, new lightweight, metal latrine chairs were introduced to the community to enable people with disabilities to use the latrines with dignity. ‘You can’t imagine how elated we were,’ Abudu recounts. ‘It allowed people with all kinds of disabilities to access sanitation facilities with great ease and comfort.’

Today, Abudu and all members of his association have latrine chairs. ‘The sanitation and hygiene of my fellow PWDs [people with disabilities] has greatly improved since we received these chairs. Now there is no struggle for us to use sanitation facilities.’ Abudu was able to return to school and is working on finishing his senior high school education. ‘Now that this chair allows me to access the facilities, there is nothing holding me back from trying to finish my studies. I also have a job at a local radio station. This intervention truly changed my life,’ he says with a big smile on his face.

*Abudu is now age 31. He shares his experiences as a child.
India: Through education I will achieve my goal – Rohit, age 14

Interviewed by Annila Harris, WV India

They call me ‘bones’ and ‘shrivelled’. It hurts very badly, but I just have to walk away. Such days I regret existing. Whenever I have a bad day or feel defeated, I question God. Why me? What are you punishing me for? What did I do to deserve being made this way? I feel anger at my condition. ‘Normal’ would have been just fine. I don’t like going out much. I find solace in staying within the house. I try to avoid being a victim of social stigma as much as possible by not going to social events like weddings because, there, people all start staring at me, as if I am a freak. They ask what illness I have and say they should stay away from me.

When I was born, the doctors made a terrible mistake. My legs were very weak and felt no sensation because I had a big boil on my back. The doctors had told my parents I needed an operation within 15 days or I would be an invalid for the rest of my life. After the operation my parents learned that the doctors accidentally cut an important nerve, but it was too late. Now I have scoliosis. I can’t grow tall or gain weight. I have little stamina, my legs hurt when I walk a lot, and my limbs are thin.

Just by looking at my physique, people pass judgment that I can’t do anything. They don’t even get to know me. Even when children my age play, they don’t include me, saying I will get hurt and I cannot contribute much in the game.

But despite it all, I still consider myself fortunate. I have hands and legs. I tell myself every day that I can do this. I can succeed if I really work hard. Thankfully I am in a school where the children don’t tease me. But my neighbourhood is not kind towards me. They see me as a freak and say rude things when I pass by. I wish they would realise that I am a human being too. I have a heart. I have feelings. We are all children at the end of the day. Even with my limitations I can do everything a normal child can do, even if it isn’t with the same intensity.

I go to school to gain an education and to disprove the stereotypical mind-set that children with special needs cannot become anything in life. Society has no hopes for me, but I have hopes for myself. I would like to tell children with special needs to be content with what they have and make the best use of it.

I live with my parents and two brothers. I am the eldest. My brothers are protective of me especially when someone says something rude to me. My mother worries about me, especially when I fall sick and I cry bitterly. She doesn’t like to see me suffer. I don’t go out much. I stay at home just to avoid rude comments. If I go out, I go with my brothers.

Through World Vision I was able to go to meetings when children with special needs came together. I got to learn about our basic rights. I never knew them before. I got to interact with other children with special needs. It is always good to know that I am not alone in this struggle. I felt a sense of belonging and oneness there. I am part of the children’s club too. I have made friends at the children’s club. My dream is to become a pilot or bank official. I will study extra hard and put in all my effort to achieve my aims and goals. Through education I will achieve my aim, my goal. My prayer is that I achieve my goals and make my parents proud. I am blessed to have a family who stands beside me. I pray to God to give me power to prove myself.
Malawi: I can become successful in life – Greford, age 16

*Interviewed by Grace Nachiola, WV Malawi*

In 2013 in Malawi, only 41 per cent of pupils passed the national examination at the end of primary school to enable admission into public secondary school. One of the children who passed the exam was a remarkable 16-year-old boy named Greford, who came from a very remote village in Malawi. He passed the exam against significant odds – including the fact that he was born without arms.

Greford was selected to go to Magawa Secondary School in Mchinji in 2014. ‘I was so happy to be selected. This gives me so much confidence and strength that I can become successful in life . . . I would like to work for the government of Malawi as a district commissioner someday,’ says Greford. He said his experience at the secondary school has been an exciting journey so far and that his future is taking shape.

A friend from his village, Fatsani, attends the same school and helps him with bathing, dressing and sometimes writing. Other times, Greford writes using his left foot.

Fatsani is one of the few people who understands Greford’s situation and has welcomed him as any other person. ‘Greford is my best friend and I love him so much. I imagine that anybody else, including me, could have been born with a disability. And that motivates me to keep helping him,’ Fatsani says.

There have been many obstacles along Greford’s journey. His secondary school was not built to be disability accessible and has never before accommodated a student with a disability. Greford needs special books, a special bed and a special desk to help accommodate his needs.

Being the only person with a disability at the school, Greford had to fight the negative perceptions of other students and even some teachers when he first arrived at the school. ‘It was not easy. My friends from my village and here at school thought I [could] not manage to stay in the boarding school . . . they saw me as stranger.’

Greford’s teacher, Mr Kapinga, said, despite various challenges, Greford’s condition does not prevent him from interacting freely with other students. He also says, ‘Greford sometimes gets so tired of writing, as he writes slowly using his left foot, but he is a stress-free person.’

Even with these challenges, Greford is one of the top students in the class. He is also an athlete. During his free time, he plays football. Greford’s journey has not been an easy one, but hopefully it will contribute to inclusion, access and equity for more children with disabilities in Malawi.
Mongolia: A dream of becoming a singer – Shirchinbaatar, age 14

Interviewed by Enkhzul Altangerel and Enkhbold Byambajav, WV Mongolia

Meet Shirchinbaatar, a 14-year-old boy living in a low-income part of town. On the surface, he appears to be just another teenage boy with a dream of becoming a singer – a vision fuelled by his passion for music. But, if you take a closer look, you will see that he is physically hindered from reaching this goal because of a disability.

Shirchinbaatar was born with his left ear completely grown over, leaving him with a hearing impairment. This meant he has never been able to hear anything at full volume. People often stared at him and teased him.

He used to feel uncomfortable in his own skin and embarrassed by his disability. ‘When I was younger, other children would point at me and call me “earless boy”. They would ask me if it was because of an accident, and when I explained that I was born this way, they would say, “How can a person be born this way?”’ shares Shirchinbaatar.

‘When I see pretty girls, I try to hide my ears because they stare at me. Some girls look down on boys with disabilities,’ he says.

There is a surgical procedure that can fix his ear. But he is not old enough to undergo the procedure because his ear is still immature for an operation. Even so, Shirchinbaatar was determined to overcome this challenge. With an undying interest in music, he found his talent in easily figuring out the right notes in any melody. Noticing his passion for music, his mother bought him an electric keyboard while working in the Czech Republic to provide for her family – a difficult challenge for a single parent.

He regularly took part in song competitions, further advancing his talent, until 2013 when he caught the attention of Erdenechuluun, the music teacher of the Children of the Blue Sky choir band, established by World Vision Mongolia. He was invited to join the band.

‘I was amazed when I first heard a choir singing. It was so harmonious. Our choir sings in three different voices, ranging from high to low. My voice is tenor. I believe that our band, Children of the Blue Sky, is the best one in Mongolia,’ he says proudly.

‘It is the best feeling to see the audience smiling and clapping when I sing. That’s why my dream is to become a singer. I want to study in the University of Arts and Culture in the future,’ shares Shirchinbaatar.

‘My mother is my best supporter. She has been encouraging me to sing since I was little,’ he adds.

His advice to other children facing challenges due to disabilities is, ‘Anything you do, you should do with determination. Take risks and never give up. Try your best to improve yourself.’
Mozambique: I want to become a teacher – Watarito, age 14

Interviewed by Ligia Francisco, WV Mozambique

I definitely feel different from other boys and my family feels different to other families. I feel like I don’t belong here. Around here nothing makes my life easier. When they want to identify my family they say ‘that family of handicapped’, as if we were from another world.

I don’t walk. I drag myself on the ground. And I have two younger brothers who are in the same situation as me. I prefer to be with them rather than with my friends. With them [his friends] I feel bad, after all, I am not like them and don’t do what they do.

It started in October 2005, after we started to eat one variety of cassava. It is bitter and it causes headaches, tiredness and dizziness. The doctors advised us not to eat it. Suddenly I started losing control of my legs and it was painful. The same thing happened to my mother, my father, my older sister, and my two younger brothers.

World Vision helped us go to the city to see the doctor. My mother recovered, but me, my father and my siblings, we did not have such luck.

After a while we had to continue to produce and eat the same cassava. We had no choice. If we produced the sweet cassava [recommended by the doctors], people used to steal it and we ended up facing hunger during the year. My mother had to take care of all of us. We felt useless, since we could not perform basic tasks like fetching water, going to the farm or even sweeping the yard.

In 2007, my father died and my sister followed a few months later, all because of that cassava.

My reality frustrates me. I have no dreams for the future. I’m just waiting for my time to go. I think I don’t have too much time.

I want to become a teacher, but I don’t dare think of going to school. Besides the fear of rejection at school, it is about 5 kilometres away from home. Just imagining the children having fun with my situation, I get afraid. Here they [the children] already mock us and look at us with pity. It is hard to drag myself, especially now that it is so hot. It seems like I am burning.

When I sleep I dream that I’m happy. I have good legs and I can run as much as I want. But then I wake up and I get more and more frustrated. Why me? God could not save us? If only my father and sister were alive.

The access roads around here are an opponent I face every day. There are thorns, spikes, thick and warm sand, and walking [crawling] is painful. Normally we go out to the street before sunrise and after sunset because the ground is not warm.

I use to bathe in the river, but I would get dirty on the way back home. It only takes two minutes. It is annoying.

Almost two months ago, we were given two wheelchairs by World Vision, a latrine for people with disabilities, and a new home for me and my brothers. I am thankful for all the things World Vision are doing for me and my family.
Mozambique: I want to help other children – Paulito, age 14

Interviewed by Pedro Leovigildo. WV Mozambique

In Chaguala community, in the historic district of Mandlakazi in the southern Gaza province of Mozambique, 14-year-old Paulo Chaguala (better known as Paulito) is a local celebrity because of his charismatic and friendly character.

His father said Paulito was born just like any other child, but when he was 3 years old, Paulito got seriously ill. Doctors tried their best but could not save him from going blind.

Paulito says he does not remember ever seeing anything in his life, but ‘I would be a doctor if I was able to see, and I would treat people, especially people with disabilities,’ says Paulito.

‘My only regret is that I am not able to do things by myself. For most things I have to rely on other people. I love karate and the other games my brothers and sisters play, but I can’t join them because I can’t see,’ Paulito says.

Paulito says that in his life, he is fortunate enough not to be a victim of exclusion and discrimination within his family and friends at school. He recounts one recent event, however, when a neighbour mocked him. ‘I was at a borehole with my brother, fetching water, when some boy mocked me because of my sight problem. I was very angry. I ran home and told my mom,’ said Paulito.

Paulito’s parents, brothers, sisters and teachers say that Paulito’s main struggle is day-to-day life, such as education, and an uncertainty over his future.

‘I am just afraid because there are many things that I have to rely on others to make happen. I wonder until when I will be living that way. At some point I am supposed to move on, and these people will also move on,’ says Paulito.

Paulito is currently doing well at school, but his passion could fade away because his future school plans are indefinite. This is because the only teacher able to give him lessons in braille was transferred to another district.

‘I won’t be going to exams this year, but I have good marks enough for a straight transition,’ said Paulito. ‘Because the teacher that was able to teach me braille is no longer here, I am waiting for a new one. But my real concern is when I go to grade eight, the secondary school here doesn’t have many teachers trained in braille spelling,’ Paulito says regretfully.

The education system in Mozambique has few schools for children with disabilities, and children with sight problems have to travel to the central province of Sofala to learn – a move Paulito’s family can’t afford.

‘But so far, I am thankful to World Vision because the teacher that was helping me here benefited from a training World Vision facilitated. This is why I say that I want to be like Sérgio Taimo, coordinator of disability project at the organisation, to help other children with disabilities, just like he helped me,’ says Paulito.
Disability Inclusion

Myanmar: To be a teacher, to share what I’ve learned – Su Su, age 14

*Interviewed by Phoebe Naw, WV Myanmar*

Su Su is a 14-year-old girl from Myanmar who contracted polio shortly after birth. She cannot walk and has to drag herself on the floor to move around the house. When her father discovered she had a disability, he abandoned her and her family. Her mother left Su Su at her relatives’ home so that she could work to support the family. However, Su Su was not treated well at her relatives’ home. Whenever issues arose between the children in the house, Su Su was blamed and scolded. Worried for her daughter, her mother eventually brought Su Su to ‘Aye Metta’ (meaning Coolness of Love), a school for children with disabilities.

This was her first time in school.

‘When Su Su arrived at the school, she was very small for her age and could not even sit well. She could not walk and whenever she tried, she fell,’ says Nwe, a teacher at the school. ‘Su Su needs love and care. Su Su never got her father’s love and hasn’t had a chance to live with her mother since she arrived here.’

At first, Su Su struggled to adjust. She had difficulty with the lessons and with using the toilet. Now, after five years at the school, Su Su can walk and move on her own. When her mother saw Su Su walking, she was overwhelmed with joy.

Su Su is happy at the school as she has teachers who take care of her and friends to play with. ‘While I stayed at home, I could not walk. When I woke up in the morning, I went to the bathroom to brush my teeth and wash my face, dragging myself on the floor. It was painful on my buttocks and also my palms. Sometimes, I got some abrasions,’ Su Su says, recalling her childhood experience.

‘I always thought that it would be good if I can walk so that I could go to school and learn,’ Su Su says. ‘I can also take care of my mom when I grow up. Now I am happy that I can go to school. I have no difficulties at school. The teachers and friends are very helpful. They help me with my lessons too.’

Su Su’s dream is to become a teacher – ‘to share what I have learned and help the children to learn’. She wishes for other children with disabilities ‘to pass high school and to graduate from the university,’ Su Su adds.

‘Thanks to World Vision for the chance to share about myself. And thank you for the support. Please let other people know about us,’ requests Su Su.
Uganda: I want to study and write a book – Herbert, age 9

Interviewed by Flavia Lanyaero, WV Uganda

Herbert can hardly talk. It takes him about 15 seconds to utter one word. Most of the time, he nods his head in agreement or shakes his head in disagreement as a way of talking back.

In addition to his inability to speak, Herbert cannot walk or use his right hand. One leg is paralysed and one hand folded, leaving him with only an arm and a leg for all his movement and work. Herbert hops from one place to another with one leg, and uses his left hand to eat, bathe or for any other daily activities.

Herbert’s grandmother, Hadijah Nabuma, says that his paralysis became apparent at about 7 months when they realised that he could not sit upright or hold items in his hands. She says that he suffered from severe malaria immediately after birth, which they suspect caused his disability.

Ms Hadijah takes care of seven orphans, including Herbert. Hebert’s parents died before he was barely 5 years old, leaving him in the care of the grandmother. There is no one to give Ms Hadijah any support, and she lives off a small garden in her backyard. She also works in people’s gardens for money and occasionally receives gifts from well-wishers and organisations like World Vision. This whole family of eight shares one small house which they use mostly for sleeping.

Because of their dire situation, Herbert has never received any professional treatment and has never been to school. His siblings go to a nearby government-facilitated school but, because he needs special care, Ms Hadijah says she does not have the means to take him to either the hospital or the school.

‘Going to school would mean he has to have a wheelchair or else I have to carry him on my back. Since he does not have a wheelchair and because I have to spend the day looking for money to feed them, I cannot ferry him to school and back every day,’ Ms Hadijah says. ‘Even going to hospital requires money. We were advised to go to Mulago hospital (Uganda’s National Referral Hospital) but I do not have money to transport us.’

Herbert, on the other hand, is more than eager to go to school. In his short conversations, he says he would very much love to wake up and go to school with his siblings. He says he would like to study and to write a book.

But, unfortunately for him, he has no access to school and is likely to remain in this state if nothing is done about his situation. Currently, World Vision in Mpigi district has provided learning materials for children with disabilities in most schools. This includes training special needs teachers and deploying them in schools, providing materials like braille machines and constructing rails, among others things.

But the challenge of getting these children from their homes to the school remains, something that requires both availability of transport and a parent’s willingness to take the child to school. For now, Herbert still needs medical care and still dreams of one day going to school. His grandmother’s wish is to have a wheelchair for him, a nearby water point, and medical bills be subsidised at the nearest health centre.
Vietnam: I want to care for my parents – Toai, age 27*

Interviewed by Tran My Hang, WV Vietnam

My name is Toai. When I was born, my appearance shocked all my family. I had no fingers and toes, and my face looked different. Only my parents dared to hold me. Nobody wanted to touch me. They were all simply frightened.

As I’ve gotten older, kids still cry when they see me and even adults run away when they see my face. They say I’m a ghost.

I didn’t have any friends in my neighbourhood, but I didn’t worry too much about what I looked like. I was aware that people didn’t like me, but I was more concerned about being a burden to my parents.

There are four people in my family. My dad is a motorbike taxi driver and my mum sells insurance, but both of their incomes are unstable. Despite that, my younger brother and I have never gone a day without food.

Before, I didn’t have a job and my brother was still young, so our parents had to cook and take care of us every day after work. They always looked exhausted and I felt useless. I kept wondering if anyone would ever give me a job or would everyone be too scared to accept me given my strange appearance? These thoughts affected me very much.

The first time I ever felt important was when my mom took me to a World Vision children’s club. I was sitting on a swing when a boy ran over and asked, ‘What’s your name?’ and ‘How old are you?’

It was the first time someone had ever done that. Hoang Anh’s questions made me really happy and, since then, he’s been one of my closest friends.

In my club, I was taught how to write and count. I also learned how to serve myself simple things so that I would not have to depend totally on my parents to do everything for me. One day, after several years at the club, I told my teacher that I wanted to start a small business selling newspapers or lottery tickets. After discussing my idea, we decided on newspapers, with World Vision giving me some money to get started.

Every day, I wake up in the early morning to deliver newspapers. After that, I go to our small shop, sitting there with my friends until 10am when all the newspapers are sold. I give all the money we make each day to my teacher, who keeps it for us and uses it to pay us a monthly salary. Each month, I earn about 600,000–700,000 dong (US$28.00–$33.00), which is enough for me and means I can help my mum when she has financial difficulties.

I used to dream about having surgery on my face, hands and feet to make me look handsome or at least normal. But now I just want my parents to have a better quality concrete house because our one is in poor condition.

I feel much happier about my life. I can walk, cycle, run and play football. Actually, I’m luckier than some of my friends in the club who have cerebral palsy or can’t move their hands or feet. And another friend doesn’t have enough money to buy a wheelchair, even though he hasn’t been able to walk for years. I hope they all have better care soon to feel useful and valuable like me.

*Toai is now age 27. He tells of his experiences as a child.
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