Missing out
A report into the experiences of deafblind children around the world
NO MORE MISSING OUT
All of us rely on our senses to understand the world. Without our senses we cannot easily comprehend our world, interact with other human beings nor go about our daily lives. Sight, hearing, touch, taste and smell enable us to interpret our environment and make decisions. Absence of one of these senses can be challenging and being without two can make life extremely difficult.

Deafblindness is a complex disability and children suffering from this condition need specialist support. Around the world, deafblind children are missing out on things that many of us take for granted on a daily basis. They are missing out on access to healthcare, education and on the opportunity to benefit from international development. Deafblind children and their families often face discrimination and are ostracised from their communities because of their disability. But all of this can be overcome.

Sense International supports deafblind children in Bangladesh, India, Romania, Peru, Tanzania, Uganda and Kenya by:

- Identifying deafblind children as early as possible so that they can receive vital assessments and support from both medical and education professionals – which will give them the best chance in life.
- Working with governments to develop suitable school and home-based education, offering training for teachers and supporting families to play their part in their child’s development.
- Providing vocational training so that deafblind people can work and participate in their own communities – for example, by helping to bring in the harvest or starting a small business.
- Working to strengthen local organisations and groups – everything from parent groups to disability organisations and governments – so that they can provide the right support for deafblind people.

However, much more needs to be done! To secure a better future for deafblind children the international community must act. The UK must ensure that aid to low income countries specifically targets the needs of children with complex disabilities. Education must be accessible for everybody; it is not acceptable that thousands of deafblind children are missing out on education because not enough teachers are specifically trained to support them and/or not enough schools are accessible and can accommodate their specific needs.

Next year the post-2015 agenda will be announced which will update the Millennium Development Goals and will set a new international agenda. It is vitally important that disability is highlighted in the updated Goals so that it is made a priority over the next fifteen years.

With the right help and support deafblind children can live, learn and thrive. It is paramount that this support is secured for future generations.

Rt Hon David Blunkett MP
Around the world deafblind children are missing out on the support they need. Many miss out on the opportunity to attend school, access healthcare and the opportunity to learn to earn a living as adults. They also face discrimination and fear of their disability. As a result, many deafblind children are shut away from society, often with only close family members knowing about their existence.

It doesn’t need to be this way and with the right help and support deafblind children can have access to the support they need and lead fulfilling lives.

Harry Astocahuana Carrión is 8 years old and lives in Lima, Peru

His family survive on a very small income and in poor overcrowded conditions. Harry is the oldest of three children.

Harry was born prematurely, and spent the first two months of his life in an incubator. When he came home from hospital, his mother Monica, quickly realised something was wrong. Harry didn’t make any eye contact or respond to changes in lighting. A trip to the hospital confirmed that he was blind. Aside from his vision loss, Harry was like any other child his age. He enjoyed playing with his mother and hearing songs. When he was three he contracted bronchial pneumonia as a result of living in damp conditions. He was hospitalised for two months and when he left the hospital he had severe hearing loss in both ears.

Harry’s father, Abel, was desperate to help him learn to communicate and engage with the outside world again. He secured his son a place at the Centre of Special Basic Education and they referred him to Sense International for specialist support. After seven months of intensive therapy Harry can now respond to simple instructions and is learning sign language. His father is amazed by the change and is delighted to see Harry becoming more independent.

Before, Harry found it hard to play with his brother and sister. Now they all play together, sharing time as a family. All these positive changes make them feel like a family unit again. Abel hopes that as Harry begins to learn a form of sign language he will become more independent and have a much brighter future.
About Sense International

Sense International is an international development charity that supports deafblind people and their families around the world. We work in Bangladesh, India, Kenya, Peru, Romania, Tanzania and Uganda and without our help and support deafblind children in these countries would lead short and lonely lives. With over 21 years of experience Sense International works closely with families and professionals to support deafblind people to develop vital communication and life skills.

Working in active partnership with local organisations and governments Sense International helps to deliver appropriate educational, health and vocational services for deafblind people. Sense International supports local disability and parent groups by offering them communication skills and training, opportunities for organisational development, and financial support. These are all vital to advocate for their needs and most importantly stop deafblind children from missing out.

Rohan is 10 years old and lives in Ahmedabad, India

When Sense International first met Rohan he was 10 years old and found abandoned on the street in Ahmedabad, India. He was unable to communicate and it was impossible to trace his parents. Frightened and thin, no one knew what his life had been like up until that point or even how long he had been alone.

Rohan is deaf and has very little sight. A doctor diagnosed him with Glaucoma, a disease which has damaged his optic nerve, leading to irreversible blindness. It was clear that he had received little or no care or support with his disability during his early years and as a result was afraid of human contact.

Rohan’s case is far from unique and the parents of disabled children regularly face social stigma and prejudice. In Rohan’s case he often became frustrated as he was unable to communicate and his parents were probably unable to cope.

He now receives training at a specialist deafblind unit where he is developing communication skills and to understand the world around him. He is now able to recognise his educator, who supports him each day and express his needs.

Jyoti, Rohan’s educator, said:

“It is a delight to work with Rohan. He has made remarkable progress and I am confident that given the continued education, training and support, he will soon become more independent.”
About deafblindness

Deafblindness is a combination of sight and hearing impairment. Some people are completely deaf and blind, but most have a little sight and/or hearing they can use. As a consequence they often struggle to undertake the most basic of daily tasks that many of us take for granted. To communicate with their parents, siblings and the outside world; to be able to act independently; and to be able to access information and even the most basic tasks such as getting on a bus can be beyond their reach.

How deafblind people communicate

There is no standard way of communicating with a deafblind person. People have a wide range of challenges, and what is suitable for one person may not work for another.

However, there are a range of approaches that can be learned and used – often in combination (known as ‘total communication’).

Some examples are:

Where a child has no communication, they might be helped to learn some simple hand signs at first (for ‘food’ for example)

They might also learn to use an ‘object of reference’ to communicate. For example, if they hold out a mug this means that they want a drink.

The people around the deafblind child can learn, though observation, to understand their body language and what they seem to want to communicate.

Some people may be able to learn a more advanced form of sign language. In Bangladesh for example, people have been learning Bangla sign language, which is an adaption of the country’s sign language for deaf people.

Without some means of communication, people will become very isolated and withdrawn, including from their family. They will become very frustrated and possibly self-harming.

Deafblindness is a spectrum and people vary enormously in the levels of their disability. At one extreme of the spectrum individuals have cognitive and physical disabilities in addition to hearing and vision loss and at the other people have hearing and vision loss but no other disability. Whether deafblindness is congenital or acquired influences an individual’s communication methods and how they identify themselves.

It is estimated that there are at least 2.85 million deafblind people amongst the 1 billion people with disabilities globally. However exact figures are not available as many deafblind people remain unaccounted for.
Chausika aged seven, lives in a village in Tanzania

She had a tough start to life and as the fifth of seven children there was a lot of competition for attention. Due to her disability she struggled to be a part of the family and was often left alone for long periods of time.

When a Sense International support worker first identified Chausika as deafblind she couldn’t walk or eat without support. Her parents had no idea what the cause of her disability was or that she couldn’t see or hear and had given up trying to communicate with her.

Over the last two years a support worker has visited the family each week and is teaching Chausika a form of tactile communication to help her communicate with her family. She has made huge progress and is now able to play with her brothers and sisters.

The main challenges facing deafblind children are:

The combined effect of having little or no sight and hearing is extremely disabling:

**Communication** – it can be very hard for someone to express their needs and make themselves understood. Their family may also feel at a loss about how to approach them.

**Isolation** – this can lead to the individual, and their family, becoming extremely isolated. Sadly, they may be ostracised from some communities.

**Getting information** – we all depend on information and feedback - for example, about what is going on around us. This is very hard for deafblind people to get without the right support.

**Mobility** – moving around safely and getting to where you want to go is very challenging.

**Independence** – living with some degree of independence is difficult, or even impossible, without receiving some education and training.

If a deafblind child in a poorer country does not receive help in these areas, there is a high chance that they will not survive.
Causes of deafblindness

Rubella during pregnancy is the main cause of children being born deafblind in developing countries, and yet there has been a vaccine since the early 1970s. In the UK, the MMR (Measles, Mumps and Rubella) vaccination means that rubella has almost disappeared from the population. Although the effects of rubella are relatively mild – someone may feel unwell, with a light temperature, sore throat and sometimes a rash – the effects of being pregnant and having rubella can be devastating on the baby.

For pregnant women particularly in the first trimester being infected with the rubella virus results in a 90% chance of delivering a baby with congenital rubella syndrome (CRS). CRS describes a range of disabling conditions which include hearing loss, visual impairment, brain damage and heart disease. Infection with the rubella virus can also result in miscarriage.

According to the Centre of Diseases Control and the World Health Organization there are estimated to be 100,000 children born with CRS annually mostly in Africa and South East Asia. The enormity and the importance of the issue cannot be underestimated. The personal devastation to be born with CRS means that most children and adults with the syndrome will require intensive support for all their lives.

The number of countries introducing the rubella vaccine is increasing year on year. However, of the 193 countries in the world currently still only 136 use the rubella vaccine as a routine part of their national immunisations programmes. The UN estimates that only this covers only 42% of the children being born globally.

In low income countries there are other significant causes of deafblindness including cerebral malaria, and meningitis as well as the effects of having inadequately resourced health services.

Many of the children Sense International supports also have other disabilities including physical and learning disabilities, feeding problems, and severe mobility problems.

Jabayer lives in Belabo in Narsingdi, which is a rural area in Bangladesh

He is four years old and lives with his parents and older brother and sister.

Shortly after he was born Jabayer began to suffer from seizures and it took three years for medication to bring these under control. The family struggle to afford this vital medication. He is completely blind and has partial hearing loss. When he was three years old he was diagnosed with cerebral palsy.

Jabayer’s family struggled to provide him with the support he needs for three lonely years. His mother wasn’t sure how to play with him or what she could do to help. Friends and neighbors became afraid of the family and avoided letting their children play with Jabayer.

He was referred to Sense International by a doctor and began to receive home visits from an educator, who came to provide rehabilitation and support. His educator, Afrina, has been working on basic activities with him such as communicating when he needs to use the toilet and eating independently. His fine motor skills are really developing so now he is able to eat. Before he could only eat liquid food but now he is able to eat solids.

Jabayer’s family have always survived on a small income from his father’s work in the fields. His mother has been given income generation support through Sense International which has helped transform the family’s finances and provide the medication he needs. His mother has been provided materials to make small stools which she can then sell. It costs around 60-70 Taka for the materials (48-56p) and from the sale of the stools she makes around 100 Taka (80p). Each day Jabayer’s mother makes one stool and is able to sell them all in a month. In a month she makes around 144 Taka or £11.41 profit.

His mother’s dream is that his health will improve and that in the future he will be able to go to school and receive an education.
Education

Disabled children have an equal right to inclusive, quality and free primary and secondary education. This universal right to primary education is enshrined in the Millennium Development Goals which determine the priorities of international development. However as the deadline of 2015 when the goals expire approaches there are still 57 million children out of school and a third of these are disabled children.

In most low- and middle-income countries, disabled children are more likely to be out of school than any other group of children and even when they attend, they are more likely to drop out or to not receive the specialist support they need.

Many deafblind children around the world miss out on the benefits of universal education. In Kenya, primary school education is free for all children. However this does not equate to being free for deafblind children. There are only three schools in the entire country that can support them and as a result parents face increased travel costs or boarding fees.

Abby Murunga is 16 years old and attends the Maseno School for deafblind people in Nairobi, Kenya

A keen learner she is being supported to learn to weave so that she can earn an income when she leaves school.

Rebecca is Abby’s mother and is a single parent to five daughters. Her husband abandoned the family shortly after Abby was born due to her disability. Up until then he had been the family’s main breadwinner and Rebecca was left with medical bills to pay as well as financially supporting her five children.

Abby was born with Congenital Rubella Syndrome and is deafblind. It wasn’t until she was two years old that she was able to sit up unaided. She has received extensive physio-therapy to improve her mobility and help her develop the muscle tone she needs to move around independently.

Due to her complex communication needs Abby is unable to attend a mainstream school. She requires one-to-one support from teacher who has been trained to communicate and work with deafblind children.

When she was 11 years old Abby was offered a place at Maseno School for the deafblind and for the first time was able to experience the joy of attending school. Her communication skills greatly improved as did her levels of independence.

Now Abby is settled at Maseno, and her mother Rebecca is a member of the Parents of Deafblind Persons, a network for parents supported by Sense International, where people can share experiences and get support from people in similar circumstances. Rebecca is a keen advocate for the rights of disabled people in Kenya and for the need for more support.
Healthcare

For many deafblind children, accessing appropriate healthcare can be a significant challenge in spite of the higher probability of requiring medical attention. These barriers are frequently divided into five categories; accessibility, including issues of discrimination, affordability, availability of services and trained personnel and quality of care.

Appropriate training and availability of healthcare professionals is critical in helping to identify deafblind children. Sense International has worked with Ministries of Health in many countries to ensure that screening programmes are available. In our experience early identification of sight and hearing loss in babies makes a marked improvement on their opportunities and on their future social, physical and psychological development.

Adela Elena Simion was born in May 2013 at Cuza Voda Maternity Unit in Iasi, Romania

She weighed only 850 grams when she was born and had a number of health problems. She was referred to a Sense International Early Intervention Support Centre by a doctor in December 2013 when it became apparent that she was unable to see or hear. When she began the early intervention programme, she was seven months old, but according to her weight and her general development, the initial assessment showed she was like a three months old baby.

Adela has received intensive therapy from experts in deafblindness. This has helped a great deal with her development and she has responded well. She is now able to sit up unaided and has begun to respond to movement.

Her parents want to provide Adela with everything necessary to lead a normal life. In the near future, they want to have Adela go through a bilateral cochlear implant and a hearing stimulation programme at the Early Intervention Support Centre. This will improve her hearing and help her learn to talk.

Daniela Simion, Adela’s mother, said:

“Adela will probably be our only child, due to medical reasons. Which is why we are determined to do anything possible to give her the best in life…”

“Adela is a fighter. She was the star of the maternity unit. Everybody was talking about her.”

“Before starting the early intervention programme, Adela did not care about playing with toys and she wasn’t interested in sounds, lights or vibrations. After many sessions of multisensory stimulation at the Sense International Romania Early Intervention Support Centre, she became very interested in playing and exploring the toys.”
Gender

The WHO and World Bank World Report on disability estimated that female prevalence of disability is as great as 60 per cent higher than that for males worldwide. Women are more likely to become disabled throughout the course of their lives and being female and disabled means you are more likely to be sicker, poorer and more isolated than disabled men or as a woman without disabilities.

Approximately 300 million of the world’s women and girls have an intellectual, mental, sensory or physical disability that leads to double discrimination and exclusion based on their gender and disability.

Despite these clear links, gender and disability have persistently been treated separately in international development.

Rojina is 15 years old and lives in a village called Moira in northern Bangladesh

The nearest town with medical facilities and schools is in the town of Bogra which is 12 km from her village. Rojina lives with her father, a truck driver who is often away for long stretches of time and her mother. She also has a younger brother and sister. The family survive on a small income and food is often scarce.

Noorjahan, Rojina’s mother, experienced a long and complicated labour. No midwife was present at the birth. Rojina has some residual sight and hearing but she didn’t receive any medical or rehabilitation support until she was seven years old. She was identified as deafblind as part of a survey of local children and referred to Sense International.

Rojina was provided with weekly support by an educator who taught her new skills including eating, washing and getting dressed independently. The educator has also helped Noorjahan learn to communicate with her daughter better.

As Rojina became more independent she was able to secure a place at a school for disabled children. She is now learning Braille and has for the first time been able to make friends. Many of the other girls in Rojina’s village do not attend school as it isn’t seen as a priority for them.

Rojina’s place at school was being put in jeopardy as the family could not afford the transport costs. Last year Noorjahan was provided with a grant to start a tea stall in front of the family home which has enabled her to generate extra income for the family.

Noorjahan said:

“We have no words to express our gratitude to the persons who have made such changes in her life. Learning how to communicate with Rojina and for her having the opportunity to attend school has changed our lives.”
International support

In 2000, the United Nations agreed the Millennium Development Goals (MDGs), which set targets for tackling poverty around the world.

Although these have had considerable success, disability is not mentioned in any of the eight MDGs, or in the 21 targets or the 60 indicators. This means that progress within the existing MDG framework has not reached disabled people because there has been no requirement to include them or address their needs.

It has been assumed that the development process will improve conditions for everyone. With the exception of MDG 3 - which promotes gender equality - development programmes have not been incentivised to address disadvantaged groups or tackle social exclusion.

The signs are however positive for the post-2015 agenda and although disability is unlikely to secure its own goal, it is likely to have a significant inclusion. There has been a proposal for a transformative shift in post-2015 development, whereby “no-one is left behind”. This would mean that targets would only be considered achieved if they are met for all relevant income and social groups, which would lead to the prioritisation of disabled people in development as a crucial step to ending poverty.

Rimu is three years old and lives with her family in Bogra, Bangladesh

Her mother, Mussamant, knew straight away that Rimu was not developing as her other children had. From an early age Rimu was struggling to feed and as a result was severely underweight and malnourished. She was unable to see and didn’t respond to sound.

Mussamant took her daughter to several doctors in the local area but they all said that there was nothing they could do to help her. She didn’t give up and took Rimu to see a specialist in Dhaka. The doctor referred Rimu to Sense International and also for her cataract operation to improve her vision.

At first Rimu was too malnourished to have the surgery as doctors feared that she would not survive the anesthetic. Over the next year an educator, provided by Sense International, worked with the family to improve her ability to swallow and take on nutrition. During that time that family raised the 75,000 taka (£594) need to fund the operation.

Since her operation life has changed dramatically for Rimu. She has begun to use speech and can lip read effectively. Her educator, Shamil, visits once a week on a Saturday and focuses on pre-school activities with her. Mussamant and her husband hope that she will be able to attend school when she turns five.
DFID does not have a disability strategy and does not have a full time disability advisor. In fact it was only in late 2013 that the department announced that schools built with its funds must be wheelchair accessible. For deafblind children and those with complex disabilities this kind of simple adaptation isn’t enough to ensure that they are included.

This is changing. At the end of 2013 the UK Parliament’s International Development Select Committee carried out its first ever inquiry into disability and development. Although DFID rejected the recommendation of a disability strategy they did promise to develop a framework and will be reporting back in November 2014 on exactly what this framework will include.

Speaking at the enquiry Edwin Osundwa, Sense International Country Representative for Kenya, said:

“I hear and experience cases where a mother who has given birth to a deafblind child, has to quit her job because she has to take care of her deafblind child. That becomes a double tragedy for the family, because that mother stops earning a very important income that would sustain the rest of the family members.

“As soon as the mother stops working, in most cases the husband may desert that family. That compounds the problems that such a family experiences.”

Hasifa is 10 years old and lives in rural Uganda

When her mother was pregnant she contracted Rubella. As a result Hasifa was born with Congenital Rubella Syndrome and has little vision and a significant hearing impairment.

The family live in a small house and make their living from the land. Because of their restricted income, education had never been a priority for the family. Until she was eight years old Hasifa received no education or support in helping her to communicate with people. As a result she was completely dependent on her mother and was unable to interact with other children her age.

When Hasifa was identified as deafblind by a health worker, she was put forward to attend a specialist programme for the deafblind at Bwanda School. She has made huge progress and her parents and teachers are beginning to understand just how bright and eager to learn she is.
Recommendations

Education
DFID must prioritise disability in its education strategy and must recognise and make provision for the different needs of children with complex disabilities including deafblindness.

Health
Universal delivery of the rubella vaccination should be prioritised by governments and donors so we can move towards the eradication of the disease.

Gender
The double discrimination experienced by women and girls with a disability needs to be addressed urgently in international development work.

International support
The post 2015 international development framework ensures ‘No one is left behind’ and in particular that disabled people are included in the next set of targets.

DFID
DFID must clearly acknowledge the needs of children with complex disabilities when reporting back with the new disability framework in November 2014 and ensure that aid programmes target their needs.