

SOS CHILDREN'S VILLAGES FORUM

Valuing diversity:
children with disabilities



SOS CHILDREN'S
VILLAGES
INTERNATIONAL



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IMPRINT

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EDITORIAL



Dear reader,

“We strive for the fulfilment of the rights of children with disabilities to play a role as full, active, and resourceful members of their communities (...)”
(Inclusion policy statement, 2008)

Between 150 and 200 million children worldwide live with a disability – this represents a staggering figure of around 10% of children across the globe¹. In the course of our work at SOS Children’s Villages, we are faced with this issue in several respects: many of the children who grow up in SOS Children’s Villages families suffer (mostly as a result of their background) from behavioural problems and underachievement, which hinder them as they grow up and become adults. The children who live in SOS Children’s Villages families are the ones who will be able to lead an independent life at a later stage. If there are no prospects of independent living as an adult, then the SOS family is not a suitable option.

In our Family Strengthening work with families of origin, it is all about giving parents and carers the support they need to deal with their children who have special needs. For instance, this can also involve us helping them to get financial support from government and non-governmental providers in order to find alternative forms of care. In any case it is vital to enable children with special needs to lead a good and dignified life, so to this end the concept of inclusion is important.

This edition of FORUM:

Including children with disabilities in everyday decision making and enabling them to take part in different spheres of life presents its own special challenges. Gerison Lansdown makes the case for lobbying for children with disabilities in “How can NGOs lobby governments to respect the rights of children with disabilities?” The central focus of another article, “The UN Convention on the Rights of Persons with Disabilities”, forms a useful framework for this topic. We also present our Inclusion Policy, and colleagues from various countries tell us about their experiences and projects relating to children with disabilities. Our travels take us to Romania, Mexico, India, Malawi and Germany. Continental Director Heinrich Müller also reports on the steps taken in Latin America to adapt the work of SOS Children’s Villages to the Inclusion Policy. Our view even extends beyond the boundaries of SOS Children’s Villages: Raquel Jelinek of Inclusion International demands inclusive education for children with disabilities and Marte Wenaas interviewed Trine Riis-Hansen, the Deputy Director of Atlas Alliance, the umbrella organisation for disabled people’s organisations in Norway.

I hope you enjoy reading this interesting edition of SOS Children’s Villages’ FORUM!

Yours,
Christian Posch

¹ Save the Children UK, 2006

VALUING DIVERSITY – VALUING DIFFERING ABILITY



© Katja Snozzi

It is estimated that there are 500 – 650 million people with disabilities in the world, approximately 10% of the world's population, 150 million of whom are children.

Children with disabilities are disproportionately more likely to live in poverty, and are at a higher risk of living without adequate parental care. They are often hidden from view or forced to live in unsuitable institutional care. Children with disabilities are four times more likely to be neglected and physically abused, and over three times more likely to be emotionally abused than other children. Their families often lack the information, support and training to cope with their specific situation.

Most causes of disabilities, such as war, illness and poverty, are preventable and early diagnosis and intervention could significantly diminish their impact on children.

THE POWER OF LANGUAGE

Language, conceptual models, terms and definitions are powerful tools both in setting and reflecting social relationships. The dynamic created by the “medical model” versus “social model” discussion of disability is related to a wider dialogue: that of charity versus human rights. The social model shifts the focus from health care and rehabilitation (medical approach) to social inclusion, based on non-discriminatory social values that value diversity, increased accessibility and visibility. The charity approach has painted people

“ Equality and empowerment of persons with disabilities is the key to any successful development outcomes. ”

Shuaib Chalklen, Special Rapporteur on Disability, to the 48th session of the Commission for Social Development¹



with impairments or functional limitations as unfortunate who must rely on the support of families and the kindness of the community or state. Today there is an historic shift towards a human rights approach to disability. People with disabilities have the same rights

as any individual, and in order to have their rights realised, they may need different but equal treatment in society.

The relatively new UN Convention on the Rights of Persons with Disabilities defines people with disabilities as: “those who have long-term physical, mental, intellectual or sensorial impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. Obviously, this definition stresses the disabling aspect of the social and physical environment, and underlines the need to understand the complex interaction between a person’s evolving capacities and the context in which that person lives.

SOS Children’s Villages has adopted the social understanding of disability. In the light of this approach, the organisation is committed to creating and working for an empowering environment for children with disabilities as well as to valuing the abilities of children with disabilities in our programmes rather than focusing on their disabilities. Furthermore, by using the term “children with disabilities” (instead of “disabled children”) SOS Children’s Villages underlines the condition of being a “child” first; “disability” is considered a secondary characteristic, albeit an important part of the individual child’s reality.

TELLING FIGURES ABOUT DISCRIMINATION²

- Over 80 % of children with disabilities live in developing countries with little or no access to services.
- The mortality rate for children with disabilities may be as high as 80 % in countries where under-five mortality as a whole has decreased to below 20 %.
- The majority of children with disabilities in developing countries remain out of school and are completely illiterate.

² UNICEF (2007), *Promoting the rights of children with disabilities*



© Christian Lesske

INCLUSION OF CHILDREN WITH DISABILITIES

As mentioned above, children with disabilities face a higher risk of losing parental care and are thus one of the most vulnerable groups of children within the target group of SOS Children's Villages. The information and reporting systems of the organisation do not provide disaggregated data on the ability or disability of children in the programmes. Therefore, no data are available on the number of children with disabilities in current programming. However, anecdotal information shows repeatedly that a significant percentage of children in the SOS programme most probably have some degree of impairment or disability.

Standard 3, Guideline 2 of the SOS Children's Village Manual (February 2004) sets down a shift from the older SOS model, defined as "only for physically and mentally healthy children", to a more inclusive one: "Children with mild physical or mental disabilities are considered for admission if their needs can be met in

an SOS family." However the organisation recognises its limitations in providing specialised care and protection for children with severe disabilities and guideline 2 further underlines: "Children with severe disabilities are referred to alternative facilities that meet their special needs more effectively."

Direct services are provided for children with disabilities in all the programmes. According to available data (2007), there are three SOS Children's Village programmes that exclusively target children with disabilities in Paraguay, India and Nepal. Worth special mention is the SOS Children's Village in Tuxtla Gutierrez (Mexico) which is at the moment the only inclusive SOS Children's Village: children with and without disabilities live together with their SOS mothers.

The SOS Family Strengthening Manual acknowledges the increased vulnerability and risk of abandonment of families of children with disabilities or of families where one of the carers is a person with a disability.



The newly developed Family Strengthening Database should provide early indication of the presence of children with disabilities within the programme and the type of services made available for them, their families and communities. However, children with disabilities tend to be invisible in the community and targeted efforts may be needed to challenge this invisibility and reach them with programmes for families of origin.

Again, given the absence of disaggregated indicators monitoring children with disabilities as beneficiaries of the SOS education services, it is impossible to estimate the number of children with disabilities in the kindergartens, schools and vocational training provided by SOS Children's Villages. However, many SOS schools are making a concerted effort to transform their curricula and their environment into an accessible and inclusive one for children with disabilities as well. Some of the schools have hired specialist teachers who work with children with disabilities within regular schools. Worth mentioning is the SOS Children's Villages Formal Education Policy, which acknowledges the need for adequate and accessible education for children with disabilities.

CHALLENGES AHEAD

SOS Children's Villages has developed and is implementing an organisational policy on children with disabilities. This policy reaffirms our commitment to working towards the social inclusion of children with disabilities, within a society which guarantees and observes the rights of these children as expressed in the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. A recent global survey (December 2010) shows that only modest progress has been achieved in the implementation of the policy on disability. Among the main reasons, beside the moderate priority of the policy in comparison to others in the organisation, are the lack of financial and human resources and the barriers set by the mindset of some co-workers.

In terms of its efforts to develop and promote an inclusive approach to children with disabilities, SOS Children's Villages shares the challenges faced by the global society. A few of them are highlighted below.

Prevention and early identification

The causes of disabilities are multiple and therefore the quality and level of prevention vary. Communicable diseases are still the cause of many disabilities around the world. Immunisation programmes, nutrition and health education should be given due priority. Lifestyle issues, such as alcohol and drug abuse during pregnancy, are also preventable causes of disabilities. Educational campaigns and good parenting programmes should tackle these issues as well.

Very often disabilities are detected quite late in children's lives, and this delay deprives them of effective treatment and rehabilitation. Early identification requires high awareness and commitment among professionals and carers working with or caring for children with disabilities. The health, educational and care programmes must allow early identification.

Children's participation in the decision-making process

More often than not, adults with and without disabilities make policies and decisions related to children with disabilities while the children themselves are left out of the process. It is essential for children with disabilities to be heard in all procedures affecting them and that their views are respected in accordance with their evolving capacities. Children themselves and their opinions should be represented in various bodies or forums where decisions affecting their lives are made. Children should be provided with whatever mode of communication they need and their families and professionals working with them need to be trained to facilitate their participation in decision-making processes, according to their evolving capacities.

Accessibility to transportation and facilities

The physical inaccessibility of public transport and other services, including health, education and recreational ones, is a major factor in the marginalisation and exclusion of children with disabilities. The existing infrastructure must become progressively accessible and new buildings must apply basic accessibility criteria.

Maximising the use of available resources

No organisation can provide all the necessary resources for the social inclusion of children with disabilities. Often these resources are available in the communities and different service providers need to acknowledge the importance of sharing these resources. Nevertheless children with disabilities and their families must be recognised in this sense as a resource for their communities.

Advocating services and resources

The recent tendency of states to reduce the budgets allocated for children has dramatically impacted on the inclusion of children with disabilities, which often ranks very low on a government's political agenda. It should not be forgotten that each state bears the ultimate responsibility for the care and protection of children with disabilities and that resources need to be made available to ensure the existence and accessibility of health care and education services for these children. NGOs must advocate for these resources not only to be made available but also to be earmarked so that they cannot be used for other purposes.

Monitoring and evaluation – include disaggregated indicators

Both governments and SOS programmes must develop mechanisms for collecting data which are accurate, standardised and allow disaggregation, and also reflect the actual situation of children with disabilities in our programmes. The importance of the issue is often overlooked and its impact on allocating the right resources and developing adequate intervention measures is diminished. Furthermore, our organisation should make additional efforts to monitor the situation of children with disabilities in our programmes, by tackling the fact that children with disabilities are often hidden by their parents or other carers.

Raluca Verweijen-Slamescu SOS Children's Villages International, Programme Development

1 www.un.org/disabilities/default.asp?navid=9&pid=1513

CHILDREN WITH DISABILITIES IN ROMANIA



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Reflections on the gaps in policy and practice

The dramatic pictures of children with disabilities in Ceausescu's Romania are now history! The country is finding ways to improve the quality of life of children with disabilities. However, some gaps still need to be filled.

A total of 680,000 people with physical, mental and social disabilities live in Romania. Almost one in ten (61,000) are children below the age of 14 (31 March 2010, National Authority for People with Disabilities).

CARE PROVISION

The state – and as such the local public authorities – bears the main responsibility for promoting and protecting the rights of children with disabilities. These responsibilities encompass: developing a legal framework and guidelines for implementation; providing structures and resources for implementation; and monitoring the access of children with disabilities and their families to the available services.

The Directorates for Social Assistance and Child Protection are responsible for the implementation of protection and care measures for children with disabilities at local level (county and district level). Following the request of parents, the directorate's evaluation services define the degree and type of disability of a given child and propose a plan for personalised services, including school orientation for the cases where this is possible. The Child Protection Commissions need to approve the individual plans. In this way, each county or district can react appropriately to the needs of children and families registered and monitored.



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Many directorates have developed:

- Rehabilitation day centres with multidisciplinary teams (psychologists, speech therapists, physiotherapists, educators)
- Mobile support teams for families of children with disabilities
- Foster care services for children with disabilities in alternative care.

Services are often provided in partnership with NGOs offering services for children with disabilities. Minimum standards for implementation have been developed to ensure the maximisation of the quality of these services.

In June 2010, the National Authority for the Family and Child Rights launched a project to build the capacity of local authorities to support the care of children with disabilities within their families. All children with disabilities have the right to a double monthly child allowance, and assistance with transportation and financial deductions; for severely disabled children a personal support person can also be hired.

Despite all these progressive measures, children with disabilities and their families are often faced with the problem of insufficient places in the specialised centres, too few professionals, a lack of specialised therapies and adequate tools for evaluation and intervention, and inappropriate or inadequate means of transportation.

The financial crisis, which seriously affected Romania, led to a significant decrease in the budgets of families of children with disabilities, and in special allowances (e.g. towards transport costs). At an institutional level, the restructuring of public services led to delays in service provision, a reduction in the number of co-workers, and the neglect of inter-institutional partnerships.

INCREASED RISK OF ABANDONMENT

The special protection and care required by a child with disabilities means an increased level of stress



© Katerina Ilievska

in his/her family and can sometimes lead to family breakdown. In the last decades of the 20th century children with disabilities were often left in the care of the state or abandoned. Romanian law 272/2004 for the protection and promotion of the rights of the child established the main responsibility for raising children and their development with their parents, while the extended family and local community are expected to support the family in its responsibilities. In addition, local authorities are required to allocate all the necessary resources and services (including recuperation and rehabilitation services) to ensure families can fulfil their responsibilities.

A negative phenomenon is the tendency of families on very low incomes to pressurise the Child Protection Commission into declaring a higher degree of disability for their children. The sad reality is that some families do not make use of the available support services targeted because they can gain more advantage from special allowances if their children have a more serious disability. There have been cases where children

without disabilities have been enrolled in schools for children with disabilities just for the sake of the after-school programme (including lunch) offered by these schools.

HEALTH PROVISIONS

Children with disabilities should have equal access to the available health services as their non-disabled peers. Since 2006 a network of centres for mental health has been developed, replacing the Mental Health Laboratories. In addition health services are provided by mobile services financed through the state health care system.

As early as 1992, the centre for mental health of the institute for the protection of the mother and of the child “Prof. Dr. Alfred Rusescu” established a day centre with educational intervention programmes and therapy for children with severe and multiple disabilities. At that time very limited state educational and therapy options were available. The children targeted by the centre were those who were unable to attend state educational institutions for reasons such as the lack of appropriate curricula, the need for specialised therapies, the lack of transport opportunities or due to the challenges presented by their behaviour or communication.

The support of a parents’ association and the commitment of the employees of the centre make it possible for the day centre to function properly. Building on this positive initiative, in partnership with the Directorate for Child Protection of the second district in Bucharest, the team of specialists successfully increased the day centre’s quality of work, as well as the number of beneficiaries (eight times more beneficiaries than when the centre opened). “In this way more methodological and financial resources were made available and an increased number of children and families had access to the services provided”, Ms. Miruna Radan, the centre’s clinical psychologist explained. Furthermore, Ms. Radan mentioned that “such centres should be seen as educational and medical (recuperative) services aimed at supporting and preparing children with disabilities to integrate within the school system. The services are child-centred. However, there is a need



© Benno Neeleman

for strong cooperation between the educational and medical services, which is absent at the moment.”

Two further policy developments are worth mentioning here, as they impact on the social inclusion of children with disabilities. Firstly, in July 2010 the government approved Law 151 on integrated specialised health, education and social services for people with conditions such as autism and associated mental health disorders in order to ensure early identification, diagnosis and multidisciplinary professional intervention. Secondly, in November 2010 the Ministry of Health signed the European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families. However the implementation of these commitments will take time, and the first results are expected by 2015.

The lack, or inefficient management, of financial resources within the medical system has had a negative impact on the situation of children with disabilities, e.g. insufficient or no medication or medical intervention, and insufficient or non-existent orthopaedic prostheses. Just to mention an example, children can benefit from a new wheelchair every five years. After three to four years and sometimes even earlier, children do however outgrow their wheelchair, and families often cannot afford to buy a new one. Generally, changes in the health care system have been slow and concrete initiatives have only happened in recent months.

EDUCATION

As Ms. Ecaterina Vrasmas, Director of the RENINCO Association and professor at the University of Bucharest says: “The discrimination against children with disabilities is a major problem within the Romanian educational system; the educational system denies access to children with disabilities and denies their rights to and chances for education. Children with disabilities are considered special children (with a negative connotation) who require special schools.” Despite some progress achieved through national or local programmes, the reality shows that many children with disabilities are still left at home, without attending school or getting support for their learning difficulties. On the other hand there is a tendency to isolate the education system from other social sectors. This leads to missed opportunities for children with disabilities to have access to education.

STIGMA, DISCRIMINATION AND MISCONCEPTION

By challenging stigma and discrimination in relation to children with disabilities, the legal framework can be improved to make it more supportive towards the inclusion of children with disabilities. Thanks to a range of different high profile media events (e.g. the fundraising competition “Dancing for you” broadcast on TV) as well as the increased visibility of services for children with disabilities in the communities, children with disabilities are nowadays more present in public life than they used to be ten or twenty years ago. In 2008, the daily newspaper “Jurnalul National” launched an awareness-raising campaign called “Special children in an autistic Romania”. The campaign was followed up by a second one called “Together for autistic children”, in 2009. In addition to which, some campaigns run by NGOs made the general public more aware of the potential of autistic children and the need for early diagnosis and intervention. One outcome of the campaign was the ratification of Law 151 (2010) mentioned above.

Atena Stoica
Senior clinical psychologist

ALEX'S STORY

Alex is the son of a woman with schizophrenia and an unknown father. He lives in a large city in Romania. Alex came to an SOS family in 1996 and remained there until 2006. Over that ten-year period he enjoyed a lot of attention from everyone, especially his SOS mother. Alex attended the special school, where he got very good results and prizes. He benefited from the support of the psychological-pedagogical team; there was also a psychologist/child development specialist who particularly supported Alex's development. The child participated in all leisure activities – celebrations, trips, travel etc. Special importance was given to regular medical check ups, as well as to providing him with his prescribed medication. Alex was introduced in to the Disabled Children Programme, launched at the level of the global SOS Children's Village association.

The SOS village director was permanently in touch with the psychologist/child development specialist in charge of his case and with the SOS mother who cared for him. He answered promptly to all the requests of the SOS mother or the team and always offered them support when requested.

At the age of 16, after completing the special schooling provided, Alex was included in an educational programme led by the Evangelical Church in Alba Iulia. There, Alex enjoyed special conditions, but more than that, a supportive and stimulating environment. Together with other teenagers with disabilities he participated in various activities which contributed to his development as an individual. Alex learned to deal with cooking responsibilities and took part in a bread baking and bakery workshop. The skills he achieved helped him later on.

At the age of 20, Alex now works on a farm, taking care of animals. The owner of the farm is very fond of him.

Thinking about Alex, the director of the SOS Children's Village where Alex grew up said: "Patience and understanding are essential in the work with children with disabilities. Treating the children in a non-discriminatory manner, including them in various activities, and encouraging socialisation through friendships are solutions that can lead to good results."

And the view of Alex's SOS mother is that: "Alex's presence in our family challenged the external as well as internal balance of the family relationships, but I think the most important thing is to be close to the child and listen to him, to guide and help him.

I was able to be close to him and it was up to me to change things in a good way: not isolating him – as was his tendency – and not being selfish. Regardless of the many difficulties we encountered, one should not forget that for a child with disabilities to grow up in the best conditions he needs first and foremost the love of the people around him.

For the other family members it was an opportunity to learn how to behave and interact when they meet such a child. The other children accepted him as their brother; they helped him, supported him, protected him and made him feel at home.

The biggest challenge for me in working with Alex was the courage to accept his impairment, helping him to understand and accept the rules I set and to trust me. In turn, I had to convince him that he is a child like all the others – a happy, protected and loved child."



THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES



© Jonas Strohwasser

Specific provisions for children

The Convention on the Rights of Persons with Disabilities¹ was adopted on 13 December 2006 at the United Nations headquarters in New York. Its aim is to elaborate in detail the rights of persons with disabilities and set out a code of implementation.

The preamble states that children with disabilities should have full enjoyment of all human rights. They shall not be separated from their parents against their will, except when the authorities determine that this is in the child's best interests, and in no case shall a child be separated from his/her parents on the basis of a disability of either the child or one or both of the parents (Article 23).

The Convention includes a specific article on children with disabilities (Article 7) which requires governments to take all necessary measures to ensure the equal rights of children with disabilities to the enjoyment of all human rights and fundamental freedoms. It emphasises the need to ensure the best interests of children, and states that governments shall ensure that children with disabilities have the right to express views, with due weight in accordance with their age and maturity. They shall also provide disability- and age-appropriate assistance to realise that right.

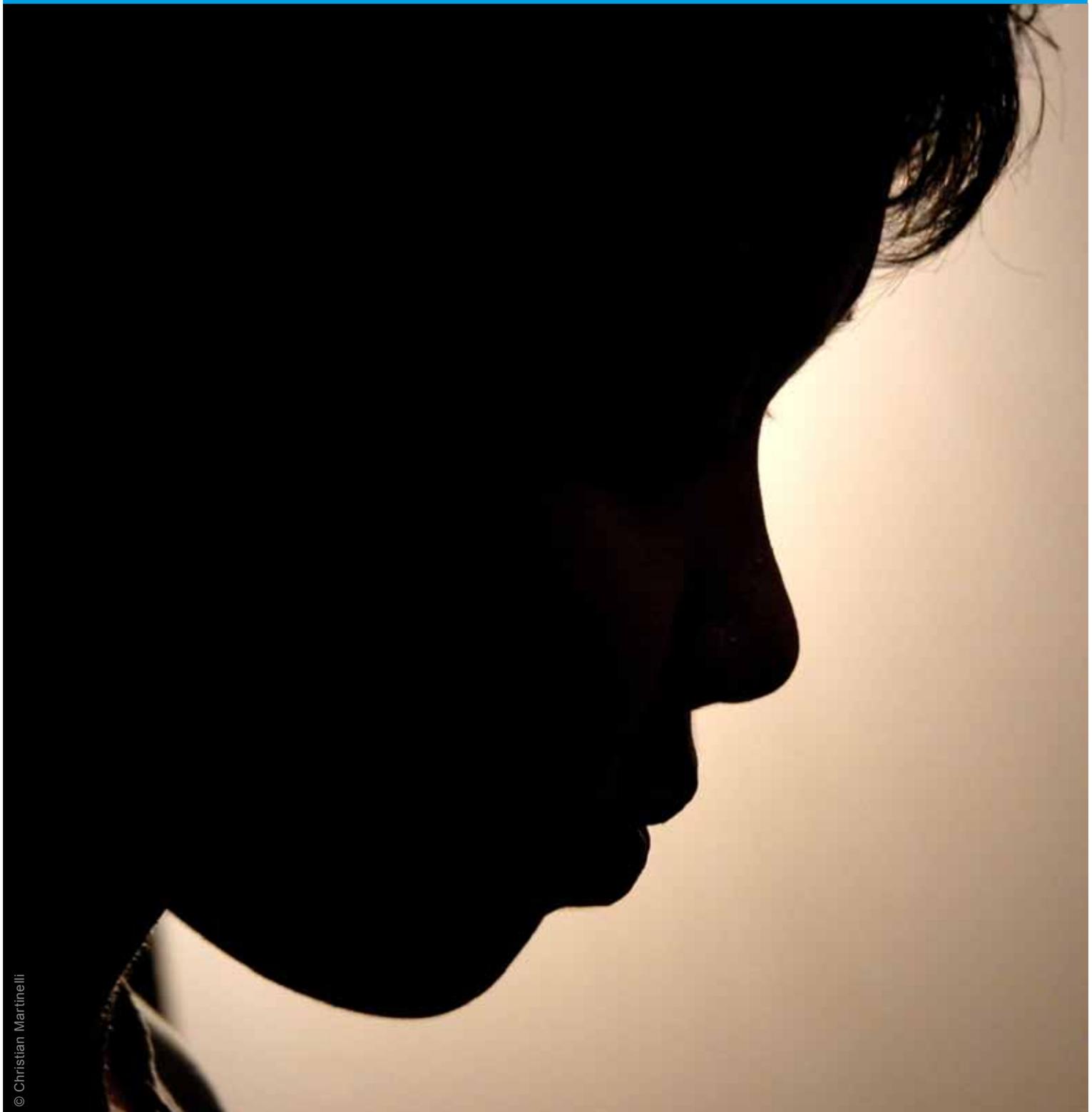
¹ www.un.org/disabilities/convention/conventionfull.shtml

FURTHERMORE, THE CONVENTION ASKS FOR:

- Respect for children’s evolving capacities (Article 3: General principles).
- Recognition of the obligation of governments, when developing laws and policies, to consult people with disabilities, including children with disabilities (Article 4: General obligations).
- Provision of age-appropriate accommodation to ensure that children with disabilities get access to justice through the courts.
- Provision of age-appropriate assistance and support in preventing all forms of exploitation, violence and abuse, provisions for the recovery and reintegration for victims of abuse which take into account age-specific needs, and the introduction of child-focused legislation and policies to ensure that violence and abuse are identified, investigated and, where appropriate, prosecuted.
- An obligation to register the birth of children with disabilities. Currently many children with disabilities are not registered, which means they often cannot get into school, access health care and they are invisible in government statistics. It can even mean children with disabilities can be killed with relative impunity as there is no record of their birth.
- The right of children to retain their fertility – in other words, a prohibition of the sterilisation of children on grounds of disability, a practice which is widespread in many countries.
- The requirement that in the case of guardianship, wardship or adoption, the best interests of the child are the paramount consideration.
- Recognition of the equal right of children with disabilities to a family life and the obligation of governments to provide information, services and support for families to prevent concealment, abandonment, neglect and segregation.
- Recognition that children with disabilities must never be separated from their parents on the basis of a disability of either the child or one or both parents – this should end the practice of institutionalising so many children with disabilities.
- The equal right of children with disabilities to education and an obligation to ensure an inclusive education system at all levels, with appropriate individualised support measures as necessary.
- An obligation to ensure that children with disabilities have equal rights to participate in play, recreation, leisure and sporting activities, including those within the school system.



THE ALTERNATIVE INTERVIEW: REWARDING & FULFILLING



Inclusive care for children with disabilities

Heinrich Müller, Deputy Secretary General and Continental Director for Latin America, Mexico and the Caribbean, talks about recent developments in our work with children with disabilities.

FORUM:

In Latin America there have been several SOS Children's Villages exclusively for children with disabilities. However, through the concept of including children with disabilities a lot has changed. How are you going to adjust to this approach?

Heinrich Müller:

The idea is to make all SOS Children's Villages for children with disabilities inclusive programmes. This means that children with disabilities will remain part of our target group but with some clear limitations. The percentage of children with disabilities should not be more than 8 to 10% and they should not need life-long care. The aim is for them to live in families together with other children where they will have the support to develop into independent adults.

If you have a closer look you will find children with disabilities in all SOS Children's Villages around the world: some of these children's impairments are due to their mother's malnutrition, some to environmental conditions; others are not even diagnosed when the children are small but become evident as the children are growing. In any case it is our task to support them to become self-sufficient.

FORUM:

What specific steps are needed to adapt existing programmes?

Heinrich Müller:

In the SOS Children's Villages Valle de Angeles in Honduras and Hogar Luz in Costa Rica over 50% of those in care are adults. Their disabilities do not allow them to live on their own: instead they require life-long support. In both countries we have been looking for partners to hand over these SOS Children's Villages.

Some months ago Hogar Luz was handed over to Catholic nuns. We have worked out a three-year plan together, meaning that we will support them during the first two years and then slowly reduce the support. In Valle de Angeles we are still in the process of finding a partner. At the same time we are reintegrating those who have family members willing to take them into their family of origin. However, 14 or 15 individuals will have to stay in the programme.

In Panambí in Paraguay and in Tuxtla in Mexico we have successfully integrated most of the children into their families of origin. In several cases these families need support which we offer them through a form of family strengthening scheme which helps them to care properly for their children with disabilities.

Panambí and Tuxtla will now start to admit children without disabilities and the remaining children with disabilities will live with them in the families. In this way, our work conforms to current standards. In Tuxtla we ran a school and a therapy centre for children with disabilities which we handed over to the government.

FORUM:

How are co-workers reacting to these changes?

Heinrich Müller:

Co-workers are very attached to the children with disabilities. Many of them have no inclination to work in an ordinary SOS Children's Village programme. Interestingly enough, for them it seems to be more demanding to work with children without disabilities. We tend to assume that it is the other way round, but they find their work with these children to be very rewarding and fulfilling. They have become used to these small steps in development and the signs of gratitude they get from the children with disabilities. However, those who want to remain with us can do so. The adjustments we are making do not represent a sudden change but a smooth process that will take some time.

YOU, US AND ALL OF US TOGETHER



© Jonas Strohwasser

Parents, carers and children with disabilities themselves are faced with many challenges when ensuring that children with disabilities lead as normal a life as possible. The following texts from Mexico, Germany and Malawi describe some of the challenges they face and the ways in which they have been resolved.

Inclusion, an evolving right

SOS Children's Village Tuxtla Gutiérrez, Mexico

SOS Children's Village Tuxtla Gutiérrez and the SOS Youth Facility there were both set up in 2003 with the idea of providing a home for children with disabilities given that then, as now, there were few services open to this group of the population. However, more often than not requests were being made to take in the siblings of children with disabilities, or friends from the same community, who had no disability at all. Our policy is always to keep siblings together and we realised that we needed to be able to provide families for children, adolescents and young people regardless of whether they had a disability or not. And so the programme has

come to be known as an "inclusive village" although in reality it was just integrating and including all the children in one home. Currently there are 70 children, adolescents and young people living in the SOS Children's Village, of whom 45 suffer from some kind of disability, such as cerebral palsy, Down's syndrome, autism, spina bifida, and visual, language or hearing difficulties to a mild, moderate or severe degree.

At the beginning of 2010 we started to restructure the child care model to meet the needs and fulfil the rights of each child, adolescent and young person. The reform is based on a holistic vision and has raised the question of what it actually means to work with an inclusion or integration model; we have come to the conclusion that we are an integration programme that is working towards total inclusion.

INTEGRATION VERSUS INCLUSION

For us, integration means forming families that can satisfy the needs, such as nutrition, health and formal education, of family members with disabilities whilst always taking the best interests of each child into account.

We are also fully aware that families need to go through the process of inclusion gradually, meaning that each member of the family takes part, to the best of their abilities, in building a home where everyone feels that their needs are met. Just being able to play a part should be cause for satisfaction. Inclusion is also based on strong family ties built within an environment where everyone is equal and that works towards ensuring that each child develops and reaches his or her full potential.

This was the launching pad for a series of actions taken to ensure that children, adolescents and young people gradually develop and become as independent as possible. The actions also aim to ensure that children, adolescents and young people are aware that they and their SOS mothers are part of a participative model where each of them plays an active role and the children are not relegated to simply being cared for.

Of course this has not been easy as most of the SOS mothers still take a rather maternal view of their role, which often means that they overprotect the children, adolescents and young people in their care, whether or not they have a disability. Some of the mothers actually said that they did not encourage their children to do housework in case this was seen as a type of abuse. This has meant that it has been a challenge for many mothers to understand that they should divide chores fairly and share their time among their children equally.



We have often talked with the mothers about how important it is for the children, adolescents and young people to take responsibility (according to their age) for their daily lives as a basis to work on to ensure that they grow up to become independent. This has also meant that the children have also had to understand that they not only have rights but also duties.

PARTICIPATING IN DECISIONS

The children, adolescents and young people, however young they may be or whether they have a disability or not, will play a larger part in the family's day-to-day life and their own quest for greater independence. They should be included in making decisions about situations that affect them, from the simplest to the most complex. For example, they should choose what to wear, do chores depending on their age and decide how they want to organise their rooms. They should also choose what they want to eat or where to go out to play, and have more chances to say how they feel and what they need so that they feel included. Changes are now being seen because the SOS mothers are investing more time and effort into teaching their children to be independent and, in some cases, results have been positive.



We are encouraging families to take more time to talk and do things together. For example, as many members of the family as possible should sit down to eat at the table at the same time or go out together even if some need help or are in a wheelchair. To make sure that the families are as integrated as possible, all family members, whether they have a disability or not, need to feel that their needs are being met.

This has meant that most of the families have seen changes in the way they interact; almost all members participate more now, despite the fact that the type and severity of disability meant that it was difficult to include some of the family members, with those members with a severe disability often finding it more difficult to participate in the family.

One great step forward has been the emotional ties that have been built between the SOS mothers and the children, adolescents and young people, and between the children. We have seen how several of the children, adolescents and young people without disabilities treat those with disabilities as if they were their siblings. For example, when those with disabilities have problems, those without disabilities show concern and offer support and vice versa, especially in times of crisis. However, when the children are all happy, shows

of solidarity increase among the siblings. It is very important for the mothers to be able to identify these emotional ties as being a mother goes beyond simply being a carer.

This relationship between the children, adolescents and young people and the SOS mothers has shown itself to be important for those with severe disabilities as they receive different types of stimulation, often lacking in a hospital setting, which helps them to become reintegrated.

The hardest part of moving from integration to inclusion has been working within the school system. The law now enables us to enrol children, adolescents and young people with disabilities in any school around the country. However, most people lack awareness of what disability means and are not trained to deal with children with disabilities and so the teachers tend to focus their teaching on children without disabilities. They show little initiative and do not take steps to adapt the curriculum to ensure that inclusion becomes a reality. Unfortunately this does not only happen in schools in Chiapas, but is widespread throughout the country. This is generally the case in the poorest regions and very much depends on the way that education policies are implemented.

INCLUSION IN ALL SETTINGS

Within SOS Children's Villages Mexico we have also seen the need to include the study of disability in the SOS mother training curriculum as the mothers themselves have requested support in this area.

Finally, it should be mentioned that including children, adolescents and young people with disabilities needs to be the case in whatever setting they find themselves, not just in the family setting. There is little point in us having an inclusive model if we continue living in a society which does not include everyone. Therefore, we need to launch community and social projects to open the way for more opportunities for development and equality.

Juan Carlos Flores Morales
SOS Children's Villages Mexico



Bringing people together

The “SOS-Kinderzentrum (SOS Children’s Centre) Garmisch-Partenkirchen”

It all began 30 years ago: a small early intervention programme with three staff members was set up, creating the SOS Children’s Centre Garmisch-Partenkirchen. Today the SOS Children’s Centre is an interdisciplinary early intervention programme with an associated meeting place for families. As well as being a centre for diagnosis, counselling and therapy, it offers a broad range of preventive services, including the Rainbow Café, theme nights, the parents’ initiative “Parents of children with disabilities” and integrative playgroups.

INTERDISCIPLINARY EARLY INTERVENTION

Working in the field of “interdisciplinary early intervention”, the Children’s Centre looks after children who have, or are thought to have, developmental syndromes or disorders, from birth until their first day at school. Cooperating closely with the parents and

taking the family and social situation into account, the SOS Children’s Centre’s aim is to help reduce existing impairments and create the conditions to support development. In this way the children and their families should be able to develop and expand their capabilities and skills, and apply them to their daily lives.

Alongside a detailed and comprehensive examination of their development status, children with a disorder receive a form of support or therapy tailored to their needs. Staff specialising in psychology, special educational needs, social learning and child development, physiotherapy, speech therapy, and occupational therapy are available to help with diagnosis, counselling, support and therapy. A paediatrician completes the team. Treatment normally takes place once a week on an outpatient basis in the rooms of the SOS Children’s Centre or through home visits to the family.

On top of this there is a specialist service provided by the SOS Children’s Centre in kindergartens, projects

VALUING DIVERSITY – VALUING DIFFERING ABILITY

Policy on the inclusion of children with disabilities

WHAT WE WANT

Children with disabilities should enjoy their rights and be able to play a role as full, active, and resourceful members of their families and communities. If they cannot be adequately cared for by their families, they should be offered alternative care that serves their best interests, with priority given to family-based care options.

WHAT WE DO

- We advocate an inclusive, non-discriminatory society, which allows and encourages children with disabilities to exercise their abilities.
- We work with families and communities to strengthen their capacity to care for and support the development of children with disabilities.
- We promote an inclusive approach in our education facilities and call for inclusive education for all children with disabilities.
- We enable children with disabilities to benefit from quality care within our family-based care programme.

TARGET GROUP

- Children with disabilities living without parental care
- Children with disabilities living at risk of losing their parental care, very often as a direct result of their disability

DEFINITIONS

When defining what “children with disabilities” means, SOS Children’s Villages uses the UN definition of people with disabilities: “Those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”¹.

By using the term “children with disabilities”, SOS Children’s Villages underlines the condition of being a “child” first; we consider “disabilities” as a secondary characteristic, one which is acknowledged as an important part of the individual child’s reality.



PRINCIPLES

- 1 The best interests of the child as a primary consideration**

All the measures taken for the protection and care of children with disabilities must be applied in the best interests of those children that have disabilities.
- 2 Ensuring access to services available in the community**

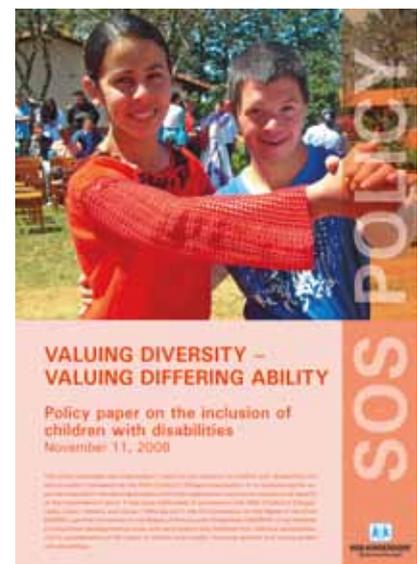
Within the community existing health, education and care services must be accessible to all children, including children with disabilities and their families.
- 3 No discrimination against children with disabilities**

Stigma, misconception and discrimination resulting in the social exclusion of children with disabilities must be addressed at all levels of society (within the family, across communities, in civil society and within state structures).
- 4 Participation of children with disabilities**

Children with disabilities must be empowered to participate in community life in a meaningful and integral way.
- 5 Working in partnerships**

Working in partnership ensures the mobilisation of the maximum resources and competencies available to achieve the most positive impact possible on the lives of children with disabilities.

1 Convention on the Rights of Persons with Disabilities, www.un.org/disabilities/convention/conventionfull.shtml, Article 1



↪ continuation from page 21

for premature babies and children at risk in co-operation with the paediatric clinic and the socio-paediatric centre in Garmisch-Partenkirchen, as well as advice in relation to newborn babies and infants with regulatory disorders (such as sleeping problems, excessive crying, eating difficulties, lack of cooperation, clinginess, or chronic restlessness).

Regular discussions with parents ensure their intense involvement throughout. Sometimes if needed, families and children receive early intervention over several years. The public authorities meet the costs of special needs education, and medical and therapeutic treatment is funded through health insurance. SOS Children's Villages bears the costs which are not covered.

RAINBOW CAFE RENDEZVOUS

The Rainbow Café is an open meeting place for families with small children. The SOS Children's Centre

sees this provision as a way of encouraging parents to exchange experiences, boost their potential for self-help, and counteract any isolation the families might suffer. The aim is to pick up and respond to education matters, problematic child-rearing situations and stress factors through measures designed to educate parents and provide stress relief. The meeting place supplements the early intervention work through preventive approaches that are self-help-related and community-based.

The following services are on offer to families in the meeting place:

- meeting place/open café hours
- open advice about social, psychological and child-rearing questions
- courses offered
- talks
- events and lots more

SOS Children's Villages makes the funding available for these services. Parents only have to pay a small amount for the courses, talks and events on offer.

Parents of children with disabilities have an opportunity to exchange ideas with affected mothers and fathers in one-to-one conversations or in the group. Within this community they realise that no-one is alone with his or her child with a disability and the associated problems. In addition these services are designed to take the burden off the families and if necessary, further support is also given.

People can make initial contacts in a relaxed environment, striking up conversations and exchanging notes, as well as enjoying a few therapeutic hours among familiar faces. Once a month, there is a discussion forum linked to a topic for parents, and children are looked after. In addition to this there is an annual weekend away for the whole family, with childcare provision to create some space for the parents and children, as well as a trip without children – just for the parents.

Adapted from texts by
SOS-Kinderzentrum Garmisch-Partenkirchen





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The power of myth

SOS Children's Villages Malawi

In Malawi, there are several myths attached to people with disabilities such as “disability is a curse from God”, “disability is contagious” or “disability is associated with witchcraft”. Such misconceptions have made it very difficult for people with disabilities to live and socialise comfortably.

SOS is likely to face similar challenges when implementing the disability policy. One issue among many is the capacity to identify congenital or acquired disabilities in children as soon as possible, thus allowing early intervention.

SOS Children's Villages Malawi is a national association that is more fortunate than others in this respect, thanks to the medical rehabilitation programme it has within SOS Children's Villages Lilongwe and Blantyre. The national office organised a country-wide disability awareness workshop for SOS mothers, which was conducted by the medical rehabilitation staff (physiotherapists, occupational therapists, and specialists in communication disorders and rehabilitation). All the mothers were taught how to identify and assist children with disabilities, making it much easier for other children and SOS mothers to understand and accept them.



The following case study is one example of the outcome of the awareness-raising workshop.

Lazaro's mother died after giving birth because they could not stop her bleeding. Lazaro was taken in by his old grandmother who could not care for him because of poverty-related issues and alcohol abuse. She fed Lazaro a local brew called "Kachaso" (similar to vodka) to send the baby into a deep sleep.

At the age of three months Lazaro was admitted to an SOS family. He was malnourished and his physical development was delayed, i.e. he had poor head control and could not roll by himself.

Lazaro's SOS mother noticed that something was wrong with his development, even though he had been put on a better diet. At the rehabilitation assessment centre the baby was diagnosed with Down's syndrome. Down's syndrome results in mental retardation and children require long-term occupational therapy and physiotherapy intervention to improve their performance in day-to-day activities.

His mother was advised to bring Lazaro for therapy three times a week and has recorded good progress ever since. Lazaro has put on weight, and is now able to sit independently; we are also teaching him how to crawl.

As much as we welcome the Inclusion Policy, it is essential to raise awareness among SOS co-workers and children about disability-related issues for the policy to be implemented effectively; otherwise children with disabilities will still face stigmatisation, segregation and isolation.

Titus Mwanjabe
Occupational Therapist
SOS Children's Villages Malawi

THE RIGHT TO BE INCLUDED



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An estimated 40 million of the 115 million children out of school have disabilities. If they are not included in schools it will be impossible to achieve the goal of universal primary education.¹

Education is based on the fundamental principle that everyone should have the opportunity to learn, and this forms the framework for including children with disabilities in primary, secondary, and tertiary education.

In recent years a number of major international statements have appeared affirming the principle of inclusive education and the importance of “working towards schools for all - institutions which include everybody, celebrate differences, support learning and respond to individual needs”. The United Nations Convention on the Rights of the Child (1989), the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993), UNESCO’s

Salamanca Statement and Framework for Action (1994) and the UN Convention for the Rights of People with Disabilities (2006) are all powerful tools in the struggle to abolish the segregated education that denies children with disabilities the right to participate in mainstream schooling and reinforces society’s prejudice and discrimination against them.

Despite all these efforts, the fact remains that “... 77 million children are not in school – and at least 25 million of them have a disability (UNESCO, 2006). Even more appalling, no more than 5% of children with disabilities complete even a primary education (World Bank, 2003). Most of those children live in developing countries.” (Global Report “Better Education for All”,

Inclusion International 2009). Inclusion is not primarily an educational or professional issue, but an issue of basic human rights that concerns everyone.

Inclusion International is a leading global federation of family organisations based on defending the human rights of people with intellectual disabilities. One of the core projects of this federation involves promoting inclusive education and calls for children with intellectual disabilities to be recognised as having the same rights as all other children and for them to receive the support they need to realise those rights.

“The quality of our education should be measured by the quality of education we promote for our most vulnerable children.”

Vianne Timmons, President Elect of IASSID – the International Association for the Scientific Study of Intellectual Disabilities

To examine how inclusive our schools are all over the world 15 years after the Declaration of Salamanca, Inclusion International asked a wide network of families, self-advocates, friends and organisations to share their experiences reflecting the reality of inclusive education.

The aim of this study was to determine the experiences of inclusion that have been successful and show that it is indeed possible to create inclusive educational environments; it also sought to identify barriers which still exist and must be overcome through joint action to find alternatives.

Undoubtedly, inclusive education has far-reaching benefits; not only children with disabilities benefit from this type of education, but society as a whole as well. The positive experiences in inclusive education help all students to have higher self-esteem, independence and socialisation; these are common factors frequently expressed by parents.

“The independence that she has now makes her the most collaborative member of our family, and a strong pillar in every sense.”

Mother of a young lady with an intellectual disability

Inclusive schools encourage the development of inclusive communities in which all people are equally valued. School is where we learn the skills that prepare us for our responsibilities as adults and where we make friends to last a lifetime. Through educating children with disabilities with their non-disabled peers, attitudes towards disability within the community change.

Parents who used to be ashamed of their children with disabilities now say that attitudes have changed, and most people in the community consider it “normal” to include children with disabilities in school.

Success can always be achieved when there are positive partnerships between parents and teachers, as well as good relations between teachers and students. Acceptance, participation and learning are lifelines for people with disabilities attending regular schools, and they appreciate the importance of academic learning and their time in school.

“If I had not gone to school, I would be ignorant; I would have to take more care of myself. Now I can do many things, I enjoy reading, listening to music, food and other things.”

Person with Asperger's Syndrome

Sadly, inclusive education is still an ideal for most countries: this is true of developing countries especially, where there is inadequate infrastructure for accessibility, poor training for teachers working with children with special needs, and widespread prejudices against people with disabilities alongside poverty and lack of opportunities.

Nevertheless, inclusive education is a social justice commitment that must become a reality.

Raquel Jelinek
President, Inclusion Interamericana

1 Source: World Bank. Cf. Education Notes, on disability and education, 2003

MEETING THE CHALLENGES



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SOS Children's Village Khajuri Kalan

An estimated 40 to 80 million people in India have a disability. But low literacy, few jobs and widespread social stigma are making disabled people among the most excluded in the country. Children with disabilities are less likely to attend school, disabled adults are more likely to be unemployed, and families with a disabled member are often worse off than average.¹ Against this background, the SOS Children's Village Khajuri Kalan in the centre of the Indian sub-continent came as a godsend for developmentally challenged children.

The aim of the SOS Children's Village is to integrate children with developmental challenges into normal life while providing tailored support and services for their special needs. First and foremost, these children need to be in normal surroundings where they can learn and grow with others. Coming as they do from diverse circumstances, these children need focused efforts which will help them to realise their potential and to participate in mainstream life.

The SOS Children's Village consists of: 14 family houses, a special activity centre, physiotherapy unit, speech therapy unit, hydrotherapy, and well-equipped medical centre, the community house, guest house, youth programme, co-worker's residence, as well as an office area and conference room. In the course of the year, more children were welcomed into permanent care, bringing the capacity of SOS Children's Village Khajuri Kalan to 90 children (45 girls and 45 boys). Children are living in the care of 13 mothers and



supported by 16 aunts and a team of co-workers who are specially trained to bring up children with special needs in the best way possible. Out of 90 children, 80 children stay in SOS families and ten young people in the youth programme.

Of these 80 children, 34 currently attend the SOS activity centre within the campus; they have a playground, as well as needs-based educational and playing materials, etc. The main focus of the activity centre is to teach children, stimulate them with an interest in life, and make them independent in terms of personal care.

Much attention is paid to performing daily activities and vocational courses that enable children to lead an independent everyday life. At present ten young people live in the youth house, attending different special schools and the vocational training centre. This year we have moved a step ahead and started the vocational training centre within the village so that young people can become self-reliant.

SPECIAL ACHIEVEMENTS

The children meet all the challenges by showing their competences in almost all spheres of life. They participated in a state-level dance and song competition organised by Sarwashwari Devi Sangeet Mahavidyalay, Bhopal and received the top trophy in the group dance category. Our children have also taken part in drawing and painting competitions organised by various organisations.

The children are well represented in sports: the Rotary Club of Bhopal Midtown organised Winter Games 2010 for children with special needs in which 25 organisations participated, including SOS Children's Village Khajuri Kalan. Various games like the spoon-and-lemon race [the equivalent of the egg-and-spoon race in some other countries] and bowls were organised in which 23 children from SOS Children's Village Khajuri Kalan also participated – one of the girls won the lemon race. She received her prize from the Director General of Police of Madhya Pradesh. A Special Olympics 2010 organised by the government of Madhya Pradesh saw ten children take part in various

events: most of the children received first or second prize in at least one of the events.

SOS MEDICAL CENTRE

A residential staff nurse, a visiting paediatrician and a psychiatrist take care of the children's medical needs. Regular health checks of all children are carried out. The nurse ensures the children receive an adequate and nutritious diet, as well as proper medication for epilepsy and other general ailments. Physiotherapy is undertaken in order to facilitate the children's developmental milestones, to reduce help with issues resulting from cerebral palsy and to increase their muscle tone and range of movement. A physiotherapist works with the children on a daily basis. At present 21 children attend physiotherapy sessions.

Twenty five children have speech problems and delayed language development. A speech therapist helps the children to communicate more effectively, and a significant improvement can be seen in them.

Hydrotherapy, which is very beneficial for children with cerebral palsy, is conducted using a play method. A co-worker helps the children to do the therapy. A homoeopathic clinic has been started on the village campus by homoeopathic practitioner Anusandhan Evam Vikas Sansthan in association with the Rotary Club Central, and a team of doctors visits every Sunday. They carry out regular check-ups on all the children, mothers, aunts and co-workers as required, and also distribute medicines free of charge.

SOS VOCATIONAL TRAINING CENTRE

The vocational training centre has been set up this year to help children to become self-reliant. The primary objective is to prepare children for integration into the outside world. However some children may take longer and we will evolve an approach based on the experience we gain as we go along.

This year we plan to include agriculture and animal husbandry, with organic farming, medicinal plants and horticulture being added the following year. A few

more courses will be also offered, including stationery printing, and making paper bags and soft toys.

Soya bean plants have been cultivated on approximately twelve acres of land, producing 2,800 kg of beans. After this successful cultivation, wheat has been grown on around ten acres of land, pulses over two acres and vegetables on a quarter of an acre. The main aim of the programme is to support our children with developmental challenges, creating normal conditions for them and making them self-reliant. The assessment of children in the over-14 age group is undertaken by the Digdarshika Institute of Rehabilitation and Research, and after their feasibility report the children become assigned to different activities.

Satyandra Kumar
Assistant Village Director,
SOS Children's Village Khajuri Kalan, India

*1 Facts taken from: The World Bank:
<http://go.worldbank.org/JIUFMTMX60>*



CHILDREN WITH DISABILITIES AND THE UN GUIDELINES FOR THE ALTERNATIVE CARE OF CHILDREN

The UN Guidelines for the Alternative Care of Children (the UN Guidelines) present a vital guiding framework to ensure, without discrimination, the child's right to development either in his/her family of origin or, when necessary, in alternative care.

For children with disabilities, in the first instance the question is how to support and strengthen the capabilities of parents and families to address and overcome the difficulties they face as a consequence of a child's disability. In the second place, where a necessity for an alternative care arrangement is identified, what should be done to ensure quality individualised care that meets the specific developmental needs of the child?

Appropriate social services to support and strengthen family capacity should focus on preventing the relinquishment, abandonment, or unnecessary removal of children with a disability from their parents and family. Promoting parental care for a child with disabilities might include a range of measures, for example providing appropriate information on relevant disability issues, financial or material assistance, or access to support services, such as day-care, respite care, and all-day schooling.





When it is not in the best interests of the child with a disability to remain with his/her parents or family, a case-by-case assessment of family capacity and the potential necessity for alternative care are required. At all stages of such a process the rights and views of the parents, family, and child should be sought and given due consideration. In essence the aim is to ensure that any placement in alternative care is a matter of necessity.

In cases of necessity the key question is what is the most appropriate form of care (e.g. kinship, fostering, or residential), in which to place a particular child. The decision on which form of care (which should also be regularly reviewed) is also guided by a case-by-case logic to appropriately individualised responses that respect and realise the rights and developmental needs of the child. Is the need for care short or long-term? Do carers have the necessary skills, knowledge and experience? What is the potential for family reintegration?

Children with disabilities who are without, or at risk of losing, parental care are a particularly vulnerable group and require appropriately targeted and individualised responses to ensure their right to life and development. In both families of origin and in alternative care settings particular efforts are required to guarantee the necessary positive and caring environment. It

is vital also to ensure the active inclusion of children with disabilities in the decision-making processes which affect their lives and secure without discrimination their rights for example, to privacy, play and leisure, health and education.

The UN Guidelines represent authoritative guidance on the implementation of the Convention on the Rights of the Child. Such guidance is necessary to ensure the inclusion of children with disabilities in families or alternative care, respecting a broad range of child rights.

Alan Kikuchi-White
SOS Children's Villages International, Programme Development

HOW CAN NGOS LOBBY GOVERNMENTS TO RESPECT THE RIGHTS OF CHILDREN WITH DISABILITIES?

Children with disabilities experience widespread violations of their rights. They are disproportionately likely to live in poverty, experience both physical and sexual violence, be denied access to education, be abandoned or rejected by their families, and live in institutional care. Recognition of these violations has grown with the widespread ratification of the Convention on the Rights of the Child (CRC) over the past 20 years. All the rights in the CRC obviously apply equally to children with disabilities, which also introduces, for the first time in international human rights law, an explicit protection from discrimination on grounds of disability, as well as a dedicated article placing obligations on states to provide services for children with disabilities to promote their fullest possible participation and inclusion. However, despite these provisions, there has been too little action, to date, on their implementation. The Convention on the Rights of Persons with Disabilities (CRPD), which was adopted by the UN General Assembly in 2006 and has since been ratified by 96 countries, provides a powerful new tool through which to make a real difference. The CRPD does not introduce new rights: people, including children, with disabilities have exactly the same rights as everyone else. What it does is to introduce new obligations for governments to implement the measures necessary to overcome the barriers that impede the realisation of rights.

For NGOs advocating the rights of children with disabilities, it is therefore important to have a clear un-

derstanding of both treaties and use the provisions of both to hold governments to account, and to consider the following approaches.

ANALYSE THE SITUATION

The first priority is to undertake an analysis of the extent to which the rights of children with disabilities are complied with, using the rights, principles, standards and obligations contained in both treaties. For example, are measures in place to ensure their right to an inclusive education? Are child protection systems sensitive to the vulnerabilities of children with disabilities to violence, and do they include measures to enable them to report violence and abuse, provide appropriate protection and rehabilitation, and ensure effective mechanisms for investigation and prosecution? Has the government taken action to ensure that the right to family life of children with disabilities is protected on an equal basis as for all other children, and that families are properly supported to care for their children? In undertaking this analysis, NGOs can use a range of sources, including legislation, regulations, government press releases and statements, court judgements, research evidence, statistical data, consultative exercises, reports from government or civil society bodies and any available data on budgetary allocations.

Having undertaken the analysis, the next challenge is to identify the roots of the problem, as this will guide the strategies and focus of advocacy. For example, is

there any legislation in place to provide protection of the right. Examples include non-discrimination legislation, social protection measures, obligations to ensure that all new buildings are accessible to people with disabilities, or a prohibition on removing children with disabilities from their families purely on ground of that disability. If legislation is not in place, then NGOs have a role to play in advocating its development and introduction. In some situations, the challenge lies not in the lack of legislation, but in a failure to implement it. Where there are no policies, resources, capacity building, dissemination or mechanisms for complaints or redress to ensure effective implementation, the focus of advocacy must be to hold governments to account in adopting the measures necessary to make legislation meaningful. And where the problem rests with a lack of capacity on the part of families to provide the level of care and support needed for their children, NGOs need to press for information as well as financial and practical support to be provided to children and their families. Lack of respect for the rights of children with disabilities may also derive from negative social and cultural attitudes, in which case, investment is needed to provide information and awareness raising to challenge the prejudice, ignorance and stereotypes often associated with disability.

BUILD NETWORKS AND ALLIANCES

Strong alliances are needed in order to be effective in advocating the rights of children with disabilities. The more people involved and the more consistent their demands, the more likely it is that governments will respond. Broad alliances also ensure the greatest possible access to the necessary range of skills, expertise and opportunities for effective advocacy. Possible partners might include sympathetic parliamentarians; networks or coalitions of disabled people's organisations; children's NGOs and community organisations; academic institutions which can undertake research on the situation of children with disabilities, thus contributing to your evidence base; editors in the print media, as well as TV and radio, including community radio, who can promote the messages you are pursuing, and inform the wider public and build awareness; professional associations and trade unions which often



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have access to the government and have experience of advocacy, as well as large memberships and the potential to reach a wide audience and national human rights institutions.

DEVELOP AN ADVOCACY STRATEGY

With both an analysis of the rights violations to be addressed and a strong cohort of individuals and organisations through which to advocate change, it is possible to develop an appropriate strategy for action. Clearly the action needed will depend on the local political and social context, but might include:



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- Raising public awareness – one of the most important activities in an advocacy campaign is to develop clear, simple messages which can be promoted in the media and wider public to build support and gather momentum. This might be reinforced through leaflets and pamphlets setting out the case for change and which can be distributed widely, press releases setting out the problem and explaining the changes being fought for and why, encouraging the media to highlight the issue, and holding conferences and workshops to promote understanding, debate and interest.
- Lobbying the government to make the changes you are advocating. It is vital when lobbying governments to provide evidence of the scale and nature of the rights violation being addressed, and the specific changes you are seeking to achieve. Offering solutions is as important as criticising failures.
- Empowering child advocates – children with disabilities can be their own most effective advocates. Action could be taken to train and support children with disabilities to work as peer advocates in school and local communities, as well as through the media and in political processes.

Where possible, meetings should be requested with the relevant ministers and government officials to discuss their obligations, and to which extent they are not are not complied with, what changes are needed and how they could be achieved and supported. In doing so, it can strengthen the case to cite any relevant existing recommendations to the government from human rights treaty bodies, such as the Committee on the Rights of the Child. Where the CRPD has not yet been ratified, campaigns to encourage governments to do so are vital.

MONITOR IMPLEMENTATION

An important part of advocacy is to monitor on-going change to assess whether there is progress in the implementation of the rights of children with disabilities. Having undertaken an initial analysis of the realisation of their rights, action can be taken on a regular basis to track changes. It is useful to construct some key benchmarks against which to monitor change. Those benchmarks can include measures to reflect:

- Changes in structures and systems – have there been changes such as governments introducing legislation, policies and programmes to fulfil, respect and protect the rights of children with disabilities, as well as providing resources and the mechanisms for accountability to ensure that they are implemented? Benchmarks might include, for example, that all relevant legislation has been reviewed to ensure that it does not discriminate against children with disabilities; policies, backed up by resources, have been introduced to provide early and comprehensive information, services and support to families with children with disabilities.
- Changes in community capacity and commitment – have there been changes at community level through services, campaigns or programmes to challenge prejudice, build support for and engage in programmes to promote the rights of children with disabilities? Benchmarks might include, for

example, that information about available services and how to access them is widely disseminated to families; or local education, health and social service providers collaborate to provide accessible integrated services for families, including early identification and assessment.

- Changes in the realisation of rights - have the measures introduced by governments, at community level and within individual programmes, resulted in improvements in the realisation of children's rights? Benchmarks might include, for example, that fewer children are placed in institutions; that more children from institutions are reintegrated in their families or in foster families; or children have access to quality early identification and assessment services.

Children with disabilities tend to be invisible in most societies in the world. Powerful and effective advocacy is needed to bring them higher upon the political agenda and to ensure that the necessary action is taken to overcome the neglect and violation of their rights. The CRC and the CRPD together provide the tools that are needed. They must be utilised to ensure that the energy and spirit that led to their creation is now translated into action at country level to achieve real change.

Gerison Lansdown
International Children's Rights Advocate



THE PERSPECTIVE OF AN ORGANISATION SUPPORTING PEOPLE WITH DISABILITIES

The Atlas Alliance

We met Deputy Director Trine Riis-Hansen in her office at the Atlas Alliance, the umbrella organisation for the development work of disabled people's organisations (DPOs) and patient's organisations in Norway. It consists of sixteen Norwegian DPOs and two affiliated organisations, all working in their specialist field (e.g. traffic victims, tuberculosis, diabetes, autism, etc). After 30 years' experience and with 70 projects in 20 countries, the Atlas Alliance works for better living conditions for people with disabilities through inclusive education, community-based rehabilitation,

health services, and the development of patients' organisations and DPOs. The Atlas Alliance is the main partner of the Norwegian Agency for Development Cooperation (Norad¹) in terms of development for people with disabilities.

1 The Norwegian Agency for Development Cooperation (Norad) is a directorate under the Norwegian Ministry of Foreign Affairs and ensures that the goals of Norway's development policy are achieved.



FORUM: What do you see as some of the main challenges in working with disability issues?

Trine Riis-Hansen: I would have to say that mainstreaming disability is a big challenge in our work. By “mainstreaming” we mean the strategy and process for making the concerns, special needs and experience of people with disabilities an integral part of all political, economic and social spheres, including legislation, policies and programmes. The ultimate goal is to achieve “disability equality”! Since the late 1990s there have been many policy initiatives around disability mainstreaming within Norwegian organisations cooperating in the area of development. Norad has for instance an impressive and progressive policy with ambitious guidelines, however so far there is little evidence that mainstreaming has been realised in practice. Although the Ministry of Foreign Affairs has taken important steps in disability issues through its work on landmines, cluster bombs and support for survivors, these efforts are very “in line with the time”, shall we say. Very often, longer term work on disability has to make way for other more popular or competing development issues. For instance our current Norwegian government gives high priority to oil-related and environmental issues. Of course people with disabilities also benefit from these focus areas, but it should not be a trade-off!

Norwegian Embassies also establish the basis for development work in the respective countries, but in general they have limited knowledge of disability issues. Therefore I would encourage people to bring this subject to their attention whenever possible.

Another important yet unfortunate factor is that disability does not appear in the Millennium Development Goals and therefore does not easily cascade down through various development initiatives. In many NGOs, working with disability is not systemic. It is important to see that disability is a cross-cutting issue that should be addressed in all development programmes and that people with disabilities must be involved in these processes. A focus on people with disabilities can also bring benefits to other groups like the elderly, younger children and pregnant women. Sometimes it is really only minor changes that are needed to make a world of difference.

FORUM: What do you mean by “inclusion of disability”?

Trine Riis-Hansen: Inclusion is about human rights, participation, self-empowerment so it means that everyone should be given the same opportunities. Inclusion is about society accepting diversity! An inclusive focus creates open-mindedness and tolerance. In a world with over 650 million people living with a disability it should really just be a natural part of life. However, people with disabilities are often made invisible, hidden away and left in poor conditions. Misconceptions about disability being a result of witchcraft, punishment etc, leads to shame, discrimination and stigmatisation. However, these attitudes are often different among children where disability has “not yet” been defined or understood as a “problem”. Therefore it is very important for children to learn about the inclusion issue from an early stage!

FORUM: Do you see any positive signs that disability is increasingly being put on the development agenda?

Trine Riis-Hansen: Yes, new policies are being developed, for example in Germany, Australia and the European Union. This is apparently a direct consequence of the new UN Convention on the Rights of Persons with Disabilities (CRPD). The CRPD is in the process of gaining momentum, ratified by China, among others, and Norway is expected to follow suit next year. This will strengthen the legal obligations of states to promote and protect the rights of persons with disabilities.

In addition, the Royal Ministry of Children, Equality and Social Inclusion says it is preparing a regulation requiring all NGO development projects receiving government support to be disability inclusive. A similar regulation for bilateral government aid is also under consideration. In addition, substantial support is given to the UN Special Rapporteur on Disability, whose key task is to promote the implementation of the CRPD. Finally, it is worth mentioning that next year the Norwegian Ministry of Foreign Affairs will host a major international conference on disability in conflict and emergency situations.

Marte Wenaas
Programme Coordinator, SOS Children's Villages Norway

A HUNDRED AND ONE USES FOR THE PROGRAMME SIMULATION



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As a staff member at SOS Children's Villages so aptly described it: "The programme simulation is a tool that helps you to smell, feel and taste the SOS Children's Village Programme Policy. It tries to harness some of your senses to give you a glimpse of what it could be when applied in practice."

Originally the programme simulation was developed to serve as an orientation tool to build an understanding of the SOS Children's Village Programme Policy and the paradigm shifts from the SOS Children's Village and the family strengthening programme as two separated forms of response towards "ONE programme". Since the start many layers have been added to the simulation to adequately address a range of issues about the SOS Children's Village programme, turning a home made board game into a complex simulation and business game.

The tool is highly versatile as it can be adapted according to the situation and realities of any SOS Children's

Village programme worldwide. Just imagine, you can draw your own map of the community you work in or download it from Google Earth; you can update the situational analysis with the information already available to you; you can recreate your existing programme responses and indicate the human resources attached to it. In other words: you can visually recreate your programme realities as they are now!

The versatility of the programme simulation contributes to the many different potential uses of the tool such as orientation, engaging with community stakeholders, doing programme reviews and planning. Let us explore some of the possible uses further.

HOW DOES IT WORK?

The programme simulation is like a board game consisting of a situational analysis, a map, tokens representing programme responses and resources such as staff, vehicles and buildings. It describes a fictitious city where children, families and their communities need support. The team's task is to plan a programme considering the different types of interventions (direct essential ser-

vices, capacity building and advocacy) and the three focus areas of care, health and education. As the budget is limited you have to think twice which responses to set up to best address the situation of children in this community. There are options to form partnerships and participants decide how to apply the resources needed (e.g. staff, vehicles and buildings).

ORIENTATION

Starting a new job and understanding the “big picture” can be challenging. The simulation can be a helpful tool to train new co-workers in their role and function within a programme. It can help them to “see” themselves in relation to programme activities and other co-workers. When combined with actual programme visits this process of visualisation will enhance and simplify the learning experience.

Even if you are with the organisation for a long time you can benefit nevertheless by playing the programme simulation! It is particularly useful for co-workers that would like to learn more about the SOS Children's Village Programme Policy or those who are not in close contact with a programme.

ENGAGING WITH COMMUNITY STAKEHOLDERS OR PARTNERS

Our programmes build on the knowledge and resources that already exist within communities. Central to this is the genuine participation of community members and stakeholders in programme development processes. The simulation can be an excellent tool to engage with community stakeholders whilst building on their knowledge. By drawing a map of their location, community members can identify community initiatives, resources and stakeholders relevant to the programme. This may include for example community churches, schools, leadership structures, gardens, youth groups, NGOs and government departments. They can also indicate challenges and problem areas within their community and point out current interventions. This information can later be used as a basis to plan programme activities and to identify potential partnerships together with community stakeholders.





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PROGRAMME REVIEWS

The simulation can be an excellent tool to review programme activities on a location level together with staff, community, NGOs or government partners. All the programme interventions, focus areas, resources and partnerships can be recreated by participants when using the programme simulation. During the process they can point out the successes and challenges they face. This information can then be used, for example, as a basis to do a SWOT analysis identifying the strengths, the weaknesses, opportunities and threats within the programme..

STRATEGIC PLANNING

The simulation has great potential for planning processes of long-term strategies on the level of national associations. One of the most common challenges in any planning process is reaching a common vision or understanding. The simulation creates an opportunity for a team to jointly visualise their programme in the future. This process of visualisation may lead to discussions and debates. The simulation can help to create an environment within which team members can challenge each other as to what they view as priority; which responses and focus areas they would like to consider and why; what the future targets and

objectives are; which existing programmes and resources must be aligned and what partnerships will be crucial to take the programme forward.

PLANNING ON LOCATION LEVEL

One of the recurring challenges with our annual planning process is how to link the location planning with the national planning process. The simulation offer teams on a location level an opportunity to simulate their plans for the following year. For example, responses in need of improvement can be identified. This may include matters such as identifying staff for further training or opening a new SOS Youth House. Once again, this may lead to debates amongst team members when reviewing existing activities and planning new ones. The end result may be a picture of the location simulation which may then be presented as input to the national planning meeting by the programme director. Yes, it is simple but it would certainly contain all the priorities for that location in the year to come.

TRY IT YOURSELF!

These are only some examples of the potential uses of the simulation. There are probably many more. All it requires is a bit of creativity, enthusiasm and the will to try something new. All of us immerse ourselves in our different areas of work, where we often lose track of the world around us. On top of that we are overloaded with information containing many abstract ideas, which does not help either. Try out the programme simulation – you will be pleasantly surprised by what it enables you to see!

Coenraad de Beer, Maria Wurzer
SOS Children's Villages International, Programme Development

If you are interested in playing the programme simulation just have a look on the Intranet: <https://intranet.sos-kd.org/areasofwork/PD/Policies/ProgrammeSimulation/Pages/default.aspx>. There you can find all the materials to create your own simulation. The programme simulation is structured in single steps and every step brings in more complexity. You can decide which steps you want to take and which not, depending on your personal needs. Have fun and let us know if you find other uses for the programme simulation by sending an e-mail to pd-service@sos-kd.org.

CHILD PROTECTION: A TOPIC FOR ALL OF US



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It is now five years since the first pilot countries began to discuss and then implement the Child Protection Policy. By introducing the Child Protection Policy, SOS Children's Villages is reinforcing its stance on and commitment to the protection of children against any form of ill-treatment, abuse, neglect and exploitation. In the meantime this position paper, which is mandatory for all national SOS Children's Villages' associations, forms the basis for a range of initiatives and measures which will allow us to ensure that the children and young people who call upon our services can grow up in a protective environment.

Explanatory procedures, training materials and a code of conduct, combined with partnerships with other organisations, help in the process of integrating child protection into the daily practice of all staff members at SOS Children's Villages. The primary focus is on awareness-raising and prevention. As the main contacts for child protection in the national associations, the National Focal Points (NFP) have special responsibility for the implementation of the Child Protection Policy and the coordination of child protection activities. To date over 100 staff members have taken part in NFP workshops. NFPs are responsible for:



- Making the Child Protection Policy accessible to all staff members and children, appropriate to their age and in the local language, and offering workshops on an ongoing basis, in order to increase awareness of every individual's responsibility.
- Improving all procedures in their respective national associations with regard to child protection; such as in the area of staff recruitment, communications and contact between children and their sponsors.
- Building and working on partnerships with other child protection organisations.

Thanks to the NFPs' intensive efforts, ill-treatment and neglect of children is no longer a taboo subject; it is easier to detect and address "boundary crossing" by SOS Children's Village staff members. A report (or complaint) and recording system provides staff members and children with a secure way of voicing their concerns or talking about specific cases of ill-treatment and neglect. The NFPs train the child protection teams and persons of trust in each programme

and they provide advice and support for management on a local and national level to take appropriate steps. In implementing the Child Protection Policy, we have also undertaken to investigate all reports of ill-treatment, abuse and neglect. There are guidelines and support materials for these internal investigations¹, as well as tailor-made training for staff members with responsibility for looking into these reports.

A first survey was conducted for the year 2009 on the implementation status of the Child Protection Policy, in which 95 out of 125 national associations (76%) took part. In the majority of countries (62%) the Child Protection Policy had already been translated into the local language(s) a year after its official adoption. In around a third of all national associations, simplified versions of the Child Protection Policy were produced for distribution to children as well. Financial resources were also invested in the implementation of the Child Protection Policy, and in 2/3 of all national associations a main representative for child protection is already in place (e.g. NFP). Almost half of all national



associations are also promoting awareness of child protection outside SOS Children's Villages. Hence approximately 30% of associations are working with partner organisations in an attempt to have a positive influence on governments: the aim is to enshrine the protection of children more firmly in national legislation. In the years ahead the education of staff members will be increasingly geared towards better support for parents in communities so that they can raise their children free from violence.

The global survey also provides basic data relating to the number and nature of reported cases of ill-treatment, abuse and neglect of children in SOS Children's Villages. The results of the survey reveal a relatively high percentage of reported cases which relate to child-to-child abuse. Training modules have been developed in conjunction with the Keeping Children Safe Coalition for staff members who work directly with children and young people on the subject of child protection. These training materials are to be used in 2011 to support a series of courses for staff members, which aim to focus children's awareness on what constitutes ill-treatment, abuse and neglect, and convey their own responsibility to protect other children and themselves.

The number of reported cases is significantly higher in those countries in which awareness-raising measures have already taken place. This confirms the assumption that the number of reported cases will rise initially because there has been an increase in the awareness of and attention paid to child protection. The fact that staff members and children are voicing concerns about child protection and reporting specific cases is proof that the reporting and documenting system in these countries is reliable and paves the way for children in SOS Children's Villages to continue to grow up in safety and to be shown respect.

Sonja Eugen
SOS Children's Villages International,
Human Resources and Organisation Development

1 Cases involving potentially criminal actions are referred to the relevant executive body for investigation.

IT'S ABOUT ABILITY – WE ALL HAVE A ROLE TO PLAY



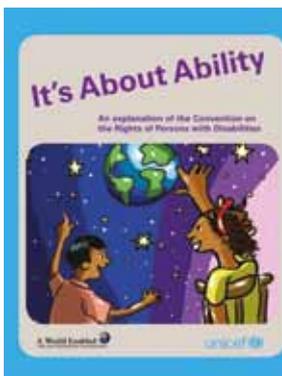
This UNICEF publication (2008) aims to encourage both children and adults to actively challenge discrimination and promote the rights of persons with disabilities. Its main message is that YOU have a role in making your community more inclusive and you can learn what actions you can take to make a difference.

Many children with disabilities, young leaders and expert consultants have participated in preparing the booklet, led by Victor Santiago Pineda (the youngest delegate co-drafting the Convention on the Rights of Persons with Disabilities) and supported by UNICEF's Child Protection and Adolescent Development and Participation Unit (with contributions from Armenia, China, Ethiopia, Nicaragua, Thailand and Uzbekistan), Save the Children UK and Sweden, and the Arab Human Rights Foundation Yemen. All these contributions are represented in the booklet with a brief version of the Convention on the Rights of Persons with Disabilities, children's drawings and poems, a chapter on "Actions for Change" and "How Rights Become Real" suggesting what YOU can do to change people's minds, such as by starting awareness campaigns, writing a petition, holding social events, doing art work

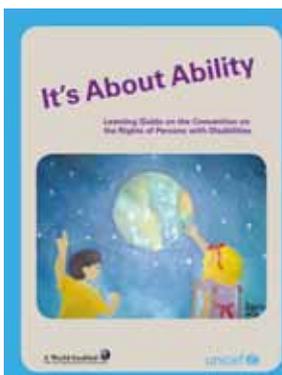
and sharing the Convention on the Rights of Persons with Disabilities with community members. The list of things you can do ends with: "The sky is the limit!"

All this makes "It's About Ability" a useful tool for training courses and awareness-building activities aimed at giving people a better understanding of the fact that people with disabilities have the same rights as everyone else. The authors encourage readers to get involved: "This book is a call for action, for children with and without disabilities to stand side by side and fight for what's right. The differences among the people of our world are a treasure for all to appreciate and share. Each child is part of the world family and contributes their unique abilities. Every child is included". With this, they support what we at SOS Children's Villages believe. We want to keep the potential of children in focus, support their individual development, promote equal opportunities and, last but not least, respect human dignity.

Bianca Helfer
SOS Children's Villages International, Programme Development



You can download "It's About Ability" free of charge and in various languages:
www.UNICEF.org/publications/index_43893.html



In 2009, UNICEF published a companion resource to "It's About Ability" with teaching and training materials that can be downloaded free of charge in various languages:
www.UNICEF.org/publications/index_50687.html

SOS CHILDREN'S VILLAGES FORUM

Valuing diversity:
children with disabilities



SOS CHILDREN'S
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