



Liliane
Fonds

open the world
for a child
with a disability

Share your Story

Learning from a Most Significant
Change pilot study

Background of the pilot study

In the last few years, the Liliane Foundation has invested in strengthening strategic partners to develop the quality of their programmes addressing the rehabilitation process of children with disabilities. Therefore, the Liliane Foundation wanted to explore which changes these children have experienced. This led to the decision to start a pilot study on the Most Significant Change (MSC) technique in Bolivia, India, Rwanda and Tanzania in 2014.

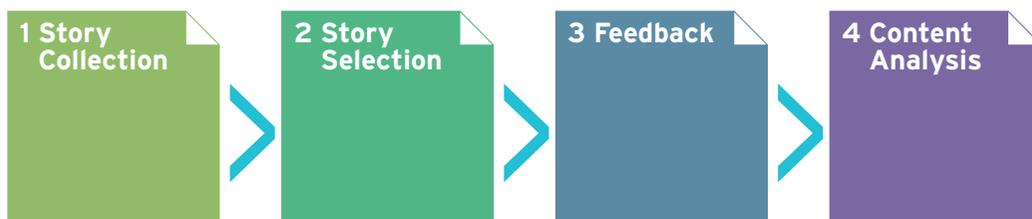
Children and youngsters with disabilities have been asked to share the changes they have experienced and to select which of these they felt were the most significant. Following this, selection committees at partner organisations (PO), strategic partner organisations (SPO) and international level selected individual stories and identified the reasons for selection.

Design of the pilot study

The MSC methodology was used to develop a pilot study. 4 key steps were identified:

- > collection of 'change stories';
- > verification of stories;
- > selection of stories;
- > feedback to the stakeholders.

For a number of stories a content analysis was undertaken, focusing on the changes the children experienced in functionality, participation, inclusive community and empowerment.



- In all 4 countries the following steps were undertaken during the MSC pilot study:
- > individual stories were collected, reflecting on the past year;
 - > both mainstream and specific partner organisations, were invited to take part;
 - > 10 children per partner organisation were interviewed, aiming for 5 girls and 5 boys;
 - > partner organisations and strategic partner organisations carried out the selection of stories;
 - > a variety of staff were invited to take part in the selection committee, including external evaluators.

The stories have been collected by several different actors, including:

- > internal staff from a partner organisation with support from an external evaluator (Rwanda/Tanzania)
- > internal staff from a strategic partner organisation (India)
- > an external evaluator (Bolivia)

By applying these different approaches, the Liliane Foundation wanted to get a better understanding of the following questions:

- > Does story collection by an external evaluator lead to more informative stories?
- > Is external facilitation more objective?
- > Does story collection by internal staff facilitate greater learning and create more ownership?

Implementation of the pilot study

In each country an experienced consultant led the implementation process, by:

- > training the local partner in the MSC technique;
- > facilitating the selection of stories;
- > safeguarding the quality of the process;
- > producing country reports on both the process and the results.



Story Collection

A central insight from the pilot was the challenge of letting children tell their own stories. For example, even when stories were largely told by children themselves, other individuals present also partly narrated the story. Mostly this was related to the type of disability of the child. Tools, such as drawings, video and pictograms, could be used to both make the interview more understandable for the child and provide them with a greater means of expressing themselves.



Lessons learned:

Stories told by a child and the family/community allow for various voices and therefore various changes will be heard, moving beyond the change at individual level. Visualization tool(s) can be beneficial when interviewing children.

The formulation of the MSC question required the child to reflect on all the changes they had experienced over the past year. The open nature of the question and the timeframe were found to be difficult to answer.



Lesson learned:

The MSC question should be related to the intervention of the partner organisation.

The design of the pilot, where collection and selection of stories was either done internally or externally, influenced who learned and what was learned. Most strategic partner organisations were only involved during the selection rounds, causing them to have learned less. The role of the strategic partner organisation in India, as facilitator, clearly shows numerous lessons that other strategic partner organisations were not able to experience.



Lessons learned:

Integration of MSC within the existing M&E activities of the strategic partner organisation resulted in more organisational learning.
Quality of stories depended on the quality of the interviewer (sufficient training and practice).
Objectivity is not guaranteed through external consultants.



Story Selection

In total, 3 levels of selection have taken place. The first one by the PO, the second by SPO and the third at international level. Each selection round brings out organisational values and criteria. The quality of the story (completeness, logic) influenced the selection rounds, although it was never used as a criterion.



Lessons learned:

Quality of the stories becomes more relevant the further you are in the selection chain.

Criteria for selection used by the partner organisations were sometimes related to physical changes (changes in functionality), although mostly related to social changes. Strategic partner organisations used the criteria: (i) changes at individual level, (ii) community level and (iii) organisational learning. The international selection committee focused more on the relation between the intervention that the child had and the perceived impact on the life of the child. Identifying criteria was often a long process and translating them into action was even more challenging.



Lessons learned:

Good facilitation of selection rounds is key for the results and learning.
Segregating stories by the narrating 'voice' (eg. parents or child) is crucial.

Discussions during the selection rounds were often held about identifying the MSC. At times the MSC defined by the child was not seen as a 'true' MSC by the committee.

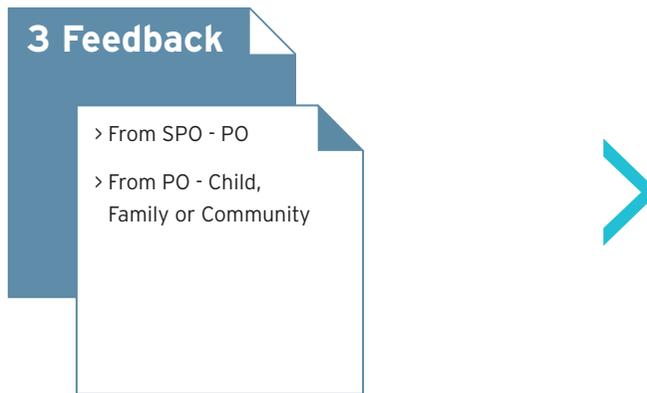
SPO: "the true MSC was something much less tangible such as 'autonomy' and 'self acceptance' which are concepts that are not always easy to pinpoint for the respondents even though they come out of the stories very clearly"

During the selection rounds organisational learnings were identified. However, six months after the pilot study, none of the participants were able to name these learnings or identify any structural changes.



Lesson learned:

Translating learnings from selection rounds into actions needs further consideration.



Feedback

After each selection round, feedback had to be sent to inform the stakeholders about the process of story selection. For example, POs had to share feedback with the communities about the story collection and selection, while SPOs had to share feedback with POs about the selection on national level. This feedback should explain which story was selected as most significant and why. Feedback about why a selection was made can expand or challenge participants' views of what is significant. Feedback also shows that others have read and engaged with the stories.

In general, providing feedback to communities was the most challenging step for partner organisations. For example, the local partners were concerned that they would cause negative feelings amongst children and families in the case that their stories were not chosen. Ethical considerations and the do no harm principle were to be taken into account. Therefore, most partner organisations only informed the communities about the learnings of MSC. In one country a booklet for each participant, including the story and a picture, was made.



Lessons learned:

Ethical, cultural and the do no harm principle need to be taken into account when providing feedback to the children and communities.

Feedback to the community needs to be well facilitated in order to be useful.

Content Analysis

From the 200 stories gathered, 60 were used for content analysis. The Liliane Foundation looked at the changes (outcomes) that children highlighted in their stories. These outcomes were coded based on the International Classification of Functioning, Disability and Health. We also looked at the interventions by the respective SPOs for these children from 2011 onwards. This was analysed and from this the following key conclusions were drawn:

- > **Participation** was a topic that was mentioned most often and by most of the children. Almost all children in the study felt that their participation had improved.

*"I'm now employed by the Government as a Secondary School Teacher."
"I like to sing during singing lessons and civic ceremonies. I participate in the band."*

- > **Inclusive community** was the topic that was least talked about. This could be because the children had not experienced any changes in this domain. However, it could also be that while some children had experienced some changes, these were not considered to be the most significant, and were therefore not mentioned in the stories.

- > **No change or negative change** It is striking that support from relatives, peers and professionals had not always changed for the better.

"My father's elder brother and my relatives don't like me as I have started walking and improving in my life; they feel jealous about me."

In understanding changes in **empowerment** we also looked at the different interventions. We can see that children indicating changes in **empowerment** had more often received assistance on each domain of intervention (health, education, livelihood and inclusion) than children not indicating changes in empowerment.

Lessons learned by (strategic) partner organisations

Alongside the lessons learned from the use of the MSC technique, the (strategic) partner organisations also indicated some learnings about the intervention approach. For example, the importance of a holistic approach and the involvement of parents, teachers and other community members were frequently named as factors that contributed to a good rehabilitation process. All (strategic) partner organisations indicated what they had learned about the outcomes of the program and the (f)actors contributing to these outcomes. Six months after the training, about 80% of the participants in the pilot study indicated that they had integrated elements of the MSC technique into their work.



Lessons learned:

The MSC technique stimulates reflection and organisational learning.

The MSC technique gives insight in the outcomes of the programme.

Qualitative monitoring and evaluation is a must to enable strategic partner organisations to have insight in the outcomes of their programmes.

Key learnings about the process of the technique

Moving from single voice stories to stories from family or community

Quality of the story is related to the capacity of the collector

The MSC question should be related to the intervention or the partner organisation

The feedback process needs special attention in order to be done well

The reasons in the selection rounds give insight into the capacity and learnings of the partner

Internal collection and facilitation leads to more ownership and capacity building

Key learnings from (strategic) partners in the pilot study

It gives us insight into the changes of our programme

Including the wider context during the rehabilitation is crucial (holistic)

We learned how to do an interview with a child

Small changes can be very valuable for the children

Future

According to the vision and mission of the Liliane Foundation, it is important to have an insight into the outcomes that the national programmes deliver for our primary beneficiaries, children with disabilities. Each strategic partner organisation can decide upon the qualitative technique that they want to use. From 2016 onwards the Liliane Foundation will invest in strengthening the capacity of our strategic partner organisations by offering knowledge and expertise in the Most Significant Change technique. The use of MSC will be in line with the current monitoring and evaluation activities which (strategic) partner organisations already undertake.

We believe that by having more insight in the outcomes for children in the national programmes, we can improve the quality of our work and adjust our approach where needed. In this regard, we continue striving for the inclusion of children and youngsters with disabilities in their communities and society at large.

The two stories that were selected by all three selection committees (PO-SPO-International)



Zebba (India): *I want to become a good teacher*

"I want to become a good teacher to illumine the minds of the younger generation with knowledge." These were the words of Zebba, an 18 years old girl from a lower socio- economic stratum staying with her mother, brothers and sister with mild intellectual disability with Cerebral Palsy. She is the third child

in the family. Her mother Haseena narrates that at the third month of her pregnancy she felt some abnormalities with the baby in the womb. She felt the child was comparatively heavier and in a scan the baby was detected with abnormal head size. During the seventh month of the pregnancy a doctor declared that the child would be intellectually disabled. As reaction to this, Haseena wanted to abort the child, however the doctors did not agree with her proposal.

Zebba was born through difficult surgery. Initially the child had no motion and was taken to the paediatrician who said that the child is special and has an intellectual disability, which means that the child had to be treated in a different way. The mother was given the tips and the advices and with a heavy heart she had to accept the reality and started treating the child in an appropriate way. She had many years of unbroken sleep and at times had to keep awake the whole night to meet the needs of the child.

Until the age of three, Zebba used to have only one position to sleep. It was her mother's duty to change the position of the child. At the age of three years the child started showing some improvements and changed her position without her mother's support. At the instruction of the doctor she used to make the child sit and feed. At the same time she continued medication for Zebba. It was the most difficult process she underwent in her life Haseena recalls! At the age of five she noticed a major change in the child that the child was trying to pick up the grains scattered before her while she was sitting. It gave a great hope to Haseena that thereafter she used to scatter grains before her so that the child could balance. At the age of seven, Zebba stood with the help of table and trying to take one or two steps ahead. "It was one of the happiest moments of my life" Haseena says!

One day as she was walking on the street, the school bus from Sampurna organization stopped at her door. The teacher from the bus noticed Zebba and met the family and proposed to admit her to the school. The family happily accepted the proposal and admitted her to the school. Being in the school there was a large change in her life. Zebba started speaking, walking, socializing and started helping in the household activi-

ties. Her mother certifies "before, I had to help her in everything, but now she started helping me". Earlier, Zebba could utter unclear words and was not able to communicate. However Haseena encouraged the child to walk and even sent the child to nearby shops in the street to purchase things. There are occasions when Zebba fell with the things that she purchased but the family was happy that she could walk. Now Zebba stops for the vehicles on the road and once the vehicle passed by she continues walking. The success of Zebba has impacted the perceptions of the community where she lives. There were more children like Zebba. They started sending their children for the special education after talking with the mother. Zebba enjoys cartoon shows and spends time in helping household activities. She washes the dishes, sweeps, mops, makes her bed and even plays cricket. She wishes to become a teacher in future. The mother says with tearful eyes: "by the birth of Zebba I had lost my sleep, but now I can sleep in peace".



Consolée (Rwanda): *Studying there where I can be myself*

What was it like before?

Before I studied in a regular school with hearing children while I am deaf. During church service I could not understand what the priest said. My father had no faith in me, even those around were not concerned about me at all. I was not allowed to watch television, nor able to understand what they said in the news.

What caused the change?

My mother took the decision to take me to the centre, and I started studying with children in the same situation as me. When it was seen that I master sign languages, I was chosen amongst the deaf students to study with the hearing in the neighbouring school which is an inclusive school. Recently my father gave me 5,000 Rwandan Franc and asked a neighbour to accompany me to the market for some groceries. Recently when I went on a holiday, those around me ran to me calling <Consolée is back>. I was filled with joy!

What was it like after?

Now I know how to communicate through sign language, and study through the inclusive education system and I am at ease in the classroom. I can understand what happens during the church service, because there are teachers who sign for us all they say. I watch television and I understand the news.

Why is this the most significant change? I regained the confidence of my father, and the neighbourhood doesn't neglect me anymore.



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