Inclusion and Deafness

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# Abstract

This paper discusses the network and community participation strategies that I found useful, effective and meaningful for the implementation of the inclusive education philosophy. Education is carried out in the community, classrooms belong to the community and education is for the benefit of the community. The core of any community is the **family**. Families may play an essential role in promoting their **deaf child's right to quality education** and participation in the community. Often communication is the greatest barrier to inclusion but more important, however, is the family's **awareness** about the hearing impairment or deafness, child's capacities and the importance of communication. Active **key persons** or change agents among families and deaf people are valuable for community awareness campaigns but often a forgotten resource in **education policy planning, decision making** and **teacher education**. Some examples of collaboration networks linking families, deaf people, community partners and education in Tanzania and Mozambique are analysed. Finally, it is suggested that education **research** also need to be linked to these networks in order to provide adequate information about developments. This information is valuable for **education sector planning**.

# Introduction

According to the UN Report on Disability and Human Rights (Despouy, 1992) most countries legally define basic education as every citizen's right. Studies among people with disabilities, however, suggest that education is usually a privilege. Social and cultural factors contribute to the low enrollment and education rates of people with disabilities (see, e.g. Cooksey & Riedmillers, 1997). In general people with hearing impairment have less access to education than people with other kind of disabilities. According to the World Federation of the Deaf, for example, approximately 80% of deaf people in the developing world have no access to education (Joutselainen, 1992).

This paper discusses my experiences of promoting education for people with hearing impairment (deaf and hard of hearing) in two developing countries, Tanzania and Mozambique during the last ten years. In Tanzania and Mozambique the term 'deafness' refer to any kind and degree of hearing impairment. In my paper I use the term the same way, even though I sometimes clarify the variety of persons with hearing impairment by subcategories, like 'deaf', 'hard-of-hearing', ' deaf from childhood' and 'using Sign language as the first language'.

In general the education sectors differ remarkably in the two countries but concerning deaf education the situation is the same. It is estimated that less than 1% of people with hearing impairment receive primary education (Vogelaar et al., 1995; Ministry of Education and Culture, 1998). Very few continue to vocational or secondary education.

# 1. The Hidden Deaf People in the Community

Education planning requires statistics and research. However, very little is known about the enrollment rates and education of the disadvantaged groups suggests E.B. Temu (1999) referring to Tanzania. It is even more difficult to provide statistics of prevalence of hearing impairment in children for education planning as there is not yet any general audiological screening of young children (see e.g. Bastos, 1998). In Mozambique, the experience of community based rehabilitation coordinators who know about the importance of early detection and intervention in the case of deafness, is that it is hard to find young deaf children. Often children are identified deaf when they are about to start school and do not speak. Sometimes the children are sent home without any information to the education authorities, health and rehabilitation workers. Without information and awareness deaf people may stay at home. Families and deaf people play an important role awareness raising. They live deafness and deaf people.

Awareness through collaboration was the key issue when we organised a training seminar for community based rehabilitation (CBR) coordinators in Mozambique in 1997. The whole training was designed so that the CBR coordinators collaborated daily with adult deaf and hard-of-hearing people and families throughout the one month course. Small teams were formed to create awareness about deafness in the local communities. Each small team consisted of CBR coordinators, deaf and hard-of-hearing adults and family members. The idea was to show the communities communication and collaboration among the team members in practise and to give an experience of deafness for the whole team. The deaf and hard-of hearing adults were prepared to show their ability to hear and their preferred ways of communication. The teams reported that many families, children, community leaders and others came with information about "similar kind" of people in the family, neighbourhood and community. In one case two families, living next to each other did not know they both had deaf family members.

# 2. Strengthening Communication within the Family Is to Strengthen the Community

Life course is continous social interaction (Clausen, 1987). First of all, a child is a family member and the family means an essential starting point for any further inclusion and participation. Communication is essential for social development, integration and learning. Deafness requires the family to learn and use alternative ways of communication. During one training session the CBR coordinators in Mozambique tried out all different kinds of communication methods to transmit some important daily messages to deaf collaborators. Observers assessed which methods worked out efficiently, in which situations, for whom (deaf, hard-of-hearing, deaf-blind) and which caused more misunderstandings.

Talking about and jointly analysing the meaning of communication most parents are astonished how much information is transmitted in the daily conversations and, therefor, how much information deaf family members constantly miss

"I never knew that she was not my mother, I grew up thinking she was my mother. It is only now I know she is my aunt, my mother's sister. I do not know why I don't live with my mother. Nobody ever told me."
(An adult deaf woman, Mozambique, 1995)

Sign language instruction, organised in collaboration with local or national associations of the deaf or other deaf instructors is important. The learning of a new language can be very effective if other forms of communication are also respected by the teachers, instead of emphasizing one language (Sign language) as the only solution to happy family life. In order to communicate some families develop home signs, others use pictures, gestures, pantomime, lip-reading and supportive signs with speech. According to interviews the experiences of deaf people vary widely with regard to their feeling of inclusion in families. Interestingly, those families that have accepted their child's hearing impairment and are aware about their child's rights manage to include him/her in the family matters, regardless their Sign language skills.

Interviewing adult deaf people and asking about their childhood memories and experiences is an effective training method. In order to converse in a collaborative way most deaf adults also need preparation as some of their childhood memories may recall the feelings of great isolation. Other families' communication experiences, their examples of deaf family members who have succeeded in school or work often reduce the social stigma sometimes attached to deafness and make parents realise their rights, opportunities and capacities.

The core of any community is the family. The crucial culture bound social and cultural values are mainly maintained and transmitted by families and non-formal education. Active families contribute to the changes in their communities, even in school. An effective part of CBR work in Mozambique is bringing families together and providing them with information and facilitating collaboration. Another important aspect seems to be provide families the life span perspective, deaf children grow up. Their childhood experiences in the families and communities form the basis of future inclusion. Adults who are deaf from childhood may enlighten this perspective of life span.

# 3. Inclusive Education and Families as Stakeholders

In general family background is a major factor contributing to the level of education (see e.g. Whitty, 1999). This may be true about deaf people as well. Both in Tanzania and Mozambique it is observed that family support has great influence on children's access to education but not necessarily to the level of education they reach. There is still very little awareness among families and communities about the right to education, that it includes also deaf people. Discussing the lack of awareness among education decision makers parents often suggest exactly the same thing:

"Let us hope and pray that the president or the prime minister will get a child with hearing impairment or at least with disability."
(A mother interviewed during a joint meeting of province level CBR and education coordinators and NGO representatives in Mozambique, 1998.)

Education is an effective selection process and awareness is needed, starting from families, as cost-sharing strengthens this selective component of education (Galabawa, 1994). Special schools, often funded by charity organisations may provide free education but far from home. Local schools may require contributions that families may hesitate to pay as there is no guarantee that the deaf child succeeds at school. Selection may cumulate to social exclusion for deaf people.

During the teacher education seminar in 1998 the Tanzanian school inspectors, head-teachers and special education teachers were asked to look at how the few special units and schools were integrated into the local communities and, secondly, into the district, regional and national education infra-structures. The main factor contributing to effective inclusion of the unit or school seemed to be the school management.

Those schools, units and teachers who reported good collaboration with the local authorities had more resources. Also, the schools/units that reported having community integration activities, were also the ones that had developed their communication competence, e.g. through Sign language courses for teachers, in collaboration with the national Deaf People's NGO. Interestingly, one school with active community and parents involvement had better security than other schools. It had obtained job opportunities for the former pupils. It was also supporting the establishment of a parents' association. In collaboration with parents the school arranged informative meetings with community leaders.

In Mozambique, active parents have a key role in advocating their children's right to education and creating awareness in education authorities. In three districts families in collaboration with the CBR coordinators have initiated special classes for deaf children within local schools. In 1998 our discussion on inclusive education with the national director of basic education was interrupted, because families and deaf people demonstrated in front of the ministry and demanded education.

Miles (1996) sees people with disabilities as an essential resource. The experience in Tanzania and Mozambique suggests that families in collaboration with deaf people contribute to more sustainable and meaningful education.

# 4. Conclusions

Instead of waiting the change to come once a powerful political person will get a deaf child and command education to happen, I would like to make some suggestions in order to bring about a significant and sustainable change:

1. Inclusion could be implemented across the education sector rather than as a national policy or as an activity at the local school level and, all education sector programmes could be inclusive.
2. There is no education without communication. Meaningful education for deaf people aims at including them in the community and society and, not only at the local school. Teacher education needs to analyse communication contexts and methods.
3. Families and deaf people are important partners or stakeholders for the implementation of inclusive education. They live in the community and deafness is their daily life. However, sometimes they need to widen their perspectives beyond the home community in order to find new solutions.
4. Conducting joint analytical and participatory planning with all community partners and stakeholders is important for locally adapted solutions.
5. Action research at international, national and regional levels could be carried out in order to create awareness and build up capacities. Research could be connected with teacher education, school management training, curriculum development and participatory community work, including various stakeholders.
6. Dissemination of information among all stakeholders needs facilitation.
7. Among education sector collaboration partners there is a need for a study on the inclusive education component as part of the general sector programme.

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