Inclusion International

SUCCESSFUL PROJECTS – WHAT MAKES THEM WORK?

A cross-national analysis

**of the studies of projects that have improved the quality of life of people with intellectual disabilities
in
India, Romania, Kenya and South Africa**

**Anders Gustavsson and Johans Sandvin
Annika and Lennart Nilsson**

Inclusion International

Table of Contents

Preface

This cross national analysis is based on national studies made by research teams in India, Kenya, Romania and South Africa. It aims to draw out the lessons learnt from successful social development processes in these countries. In each country, studies have been made of projects identified as interesting, successful and/or outstanding in the way they have improved the quality of life of people with intellectual disabilities. In national reports, the respective teams have made their own national conclusions.

This comparative report briefly describes the national studies. It then continues with a cross national analysis attempting to identify circumstances or factors that are common to these successful projects. Finally, the report summarises the conclusions and their implications. We hope that the findings presented in the report will be used as inspiration in future planning, implementation and funding of projects aiming at improving life conditions of groups that are marginalised in society.

Chapter 1 and 2, describing the research process and the national reports have been written by Annika and Lennart Nilsson. Anders Gustavsson and Johans Sandvin are responsible for the cross national analysis in chapter 3 to 7. The conclusions and implications in chapter 8 have been written jointly.

The study has been commissioned by Inclusion International and financed by the Swedish International Development Agency (Sida).

Acknowledgement

This study would not have been possible without the collaboration of the national coordinators and their teams; this report is the result of our joint efforts. We extend our sincere thanks to the coordinators Dr Suneeta Kulkarni, India, Ms Washeila Sait, South Africa, Dr Mircea Alexiu, Romania, Ms Margaret Morumbasi, Kenya and their respective teams. It is their achievement as much as ours.

We would also like to thank the reference group for the advice and support provided throughout the process: Victor Wahlström and Fred Heddell, Inclusion International, Barbro Carlsson, disability activist and Tiina Nummi Södergren/Malin Ekman-Aldén, Swedish Organisations of Disabled Persons, International Aid Association (SHIA).

We also thank Inclusion International for the confidence and Sida for providing the financial support. A special thanks to Eva Falkenberg, Disability Advisor at Sida who supported our research idea from the very start.

Last but not least we extend our thanks to everyone in the projects who has volunteered to share their views and feelings to help us understand what made the projects so exceptional. Without their willingness to contribute this study would not have been possible. They have told their stories in the hope of influencing development and contributing to more efficient programmes that will improve living conditions of people with disabilities and their families. We hope this report will do justice to what they said and lead to the implementation of practical measures and improvements in the quality of life for people with disabilities.

Chapter 1 - Introduction

The objective of the cross-national analysis
The first phase of the study explores social development processes – the projects. The four national teams identified the successful projects in their own country. Success was seen in terms of bringing about outstanding changes and improvements in the quality of life of people with intellectual disabilities in the specific national contexts.

The comparative report represents the second phase of the study and consists of a cross national analysis. This aims to identify circumstances and factors of importance for these outstanding developmental projects. The intention is to provide information about these circumstances and factors to influence and improve future planning and implementation of projects, as well as funding decisions.

Definition of Intellectual Disability
In this study, the following definition of intellectual disability has been used[1]:

Intellectual disability is a condition where people have significant difficulties in learning and understanding due to an incomplete development of intelligence. Their skills in areas such as cognition, language, motor and social abilities can be permanently impaired. Between one percent and three percent of a population has an intellectual disability.

A person with intellectual disability has life-long developmental needs. Intellectual disability is a condition of slow intellectual development, where medication has no effect. Intellectual disability can be caused by genetic factors or by environmental factors, such as infections, or by a lack of oxygen supply to the brain during pregnancy or at birth. Intellectual disability is not normally caused by social or psychological factors. Difficulties in learning and understanding lead to problems at school, in working life and participating in the regular life of society. There is a large variety of appearances and degrees of intellectual disability requiring different forms of therapies or support. Intellectual disability is permanent.

Intellectual disability is different from mental illness. Mental illness is an illness and can be cured, whereas intellectual disability is a life-long condition. People with mental illness need mental health care, medical and psycho-therapies. In general, they have no intellectual impairment and can live independently when their mental health problem is controlled. People with intellectual disability are not ill, unless they have a common illness. They need easy-to-understand information, education or training to live as part of society.

In the study we have avoided terminology that can be seen as offensive such as "mental retardation" and "the mentally retarded", even though these terms are officially used in some countries - even in legislation. We have also avoided the term "handicap" as it is used less and less about people.

---

[1] Inclusion International information leaflet

Although the focus of the study has been on children and adults with intellectual disabilities, some of the projects selected by the national teams also include other disability groups.

Background and aims

Almost all development initiatives are planned and implemented to improve the life conditions of poor and disadvantaged groups. These initiatives use various strategies to achieve change in attitudes, legislation, services, practices, resource allocation etc. Increasingly, the strategies include efforts to empower people and civil society organisations to become strong change agents in their respective communities and countries.

In 1998, Inclusion International together with Swedish Organisations of Disabled Persons, International Aid Association (SHIA) and the Swedish National Society for Persons with Mental Handicap (FUB) agreed to support a collaborative project called "Global Project on Human Rights/UN Standard Rules" with the following three components:

1. To influence UN bodies, to increase the use of the UN Standard Rules and other UN Human Rights instruments, to monitor the rights of people with disabilities in general and children and adults with intellectual disabilities in particular.

2. To achieve sustainable improvements in the conditions of children and adults with intellectual disabilities in Kenya, India and Romania through
   - Influencing decision makers and authorities to implement the UN Standard Rules
   - Supporting NGOs fighting for the rights of children and adults with intellectual disabilities
   - Forming and supporting Parent Mobilisation Action Groups (PMAGs)
   - Using models developed in South Africa as a source of inspiration

3. To study the processes and methods described above - as well as other initiatives - identifying the most successful ways of achieving sustainable improvements in the conditions of children and adults with intellectual disabilities.

The study was intended to be the third part of the project. However, it became difficult to find funding for the study as originally planned. Therefore the terms of reference were redefined and the study was developed into an independent research project with its own organisation. Also the role of South Africa was changed. In the study, all countries have participated on an equal basis.

In the redefined terms of reference it was agreed that the aim of the study should be: "to explore, describe and understand successful change processes and learn from them". The following specific questions were to be addressed:
   - Which projects resulting in sustainable improvements of life conditions for adults and children with intellectual disabilities can be found in the four countries?
   - What are the most strategic change agents, internationally, nationally and locally?

- Which methods are most effective at initiating and maintaining the processes of change?
- What other factors, deliberate project interventions as well as contextual factors, are important to achieve a positive change?

Organisation of the Study

The study has been guided by a Reference Group based in Sweden[2], appointed by Inclusion International. The coordination and monitoring of the research process was carried out by two Swedish consultants and two university professors with extensive experience of research in the disability field. To ensure local ownership and cultural and contextual relevance of the study, research teams consisting of four – six people were also established in each country.
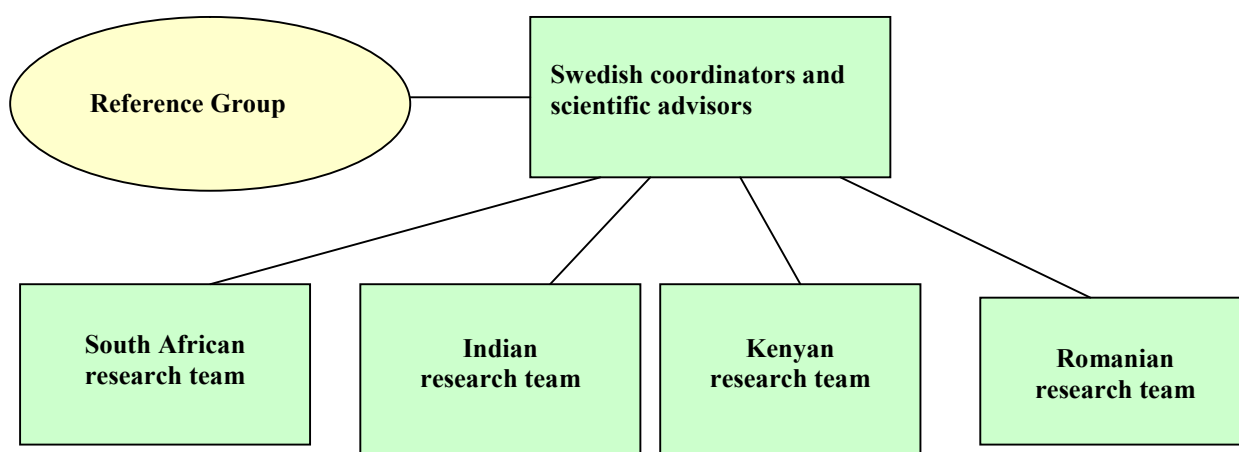
It was a lengthy process identifying coordinators and team members in the four countries with the human rights values, experience and knowledge required to guide and carry out the national studies. The language requirement (English) also limited the selection in one country. The following guidelines were used to identify team members:

- The teams should include one person with a post-graduate academic qualification (PhD or similar research background) to ensure the scientific credibility of the study. This person should also have disability or social sciences experience.
- The team should include two representatives from the disability movement to ensure a user perspective of the study. At least one of them should be a parent from the Inclusion International partner organisation[3].
- If there is a national institute on research with competence in the disability area, this institute should be represented on the team to facilitate a national approach and bring a wider perspective to the study.
- The team should have a team coordinator responsible for the actual planning and implementation of the study and for the timely reporting to the coordinators in Sweden. The Inclusion International partner organisation in each country should select and/or approve the national team coordinator.

---

[2]Barbro Carlsson Chairperson, Viktor Wahlström ex-president of Inclusion International, Fred Heddell treasurer of Inclusion International, Tiina Nummi-Södergren/Malin Ekman-Aldén of SHIA, Professor Anders Gustavsson, Stockholm University who has served as a scientific adviser and Annika and Lennart Nilsson responsible for coordination, administration and reporting of the study. In addition Professor Johans Sandvin of Bodö University in Norway has been attached to the group as an additional scientific advisor.

[3] Parivaar in India, Inclusion from Romania in Romania, DICAG and DSSA in South Africa and KAIH in Kenya.

The intention was to ensure user perspective and user ownership while at the same time ensuring high academic standards of the study. The Inclusion International partner organisation (parent association/federation) in each country was given the responsibility of monitoring the study's budget and selecting/approving the coordinator. The process of selecting and informing the team members of their responsibilities took considerable time and included interviews with government officials and representatives of disability organisations and research institutes in all four countries. CVs were submitted for all team members and terms of reference were provided for everyone committing themselves to the national teams. The main tasks of the team members were:

- Assist the team coordinator to develop the national selection criteria for the identification of the examples (projects) to be studied.
- Take responsibility for the selection of the examples to be studied.
- Comment on the research tools proposed by the team coordinator regarding scientific qualities as well as practical usefulness.
- Assist the team coordinator in the data generation and the analysis of the case studies.
- Comment on the preliminary findings and critically analyse and comment on the draft report prepared, thus helping the team coordinator who was the formal author.

The selection of team members turned out to be quite a controversial and politically sensitive matter and in most countries there were people, organisations and research institutions that felt bypassed. Tensions also arose within some of the teams as members had different roles to play and different experiences of research. It was intentional to bring different people together, and to balance possible conflicting interests such as the academic and user perspectives. It was assumed this would benefit the process, improve the quality of the research and facilitate the future dissemination and use of the findings. In a few cases however, the tensions had a negative effect on the process.

In conclusion, although the parent associations/federations had financial and monitoring powers most did not involve themselves extensively in the research process. Only towards the end, when findings were starting to emerge, did some of the parent organisations take interest and claim ownership. The national coordinators played a crucial role in driving the research process forward. In some countries, the team members made substantial contributions. The team members in all countries should be commended for completing their tasks successfully despite the challenges during the research process.

A semi-structured collaborative research design
The original idea was to find a common frame of reference to identify and evaluate improvements in the living conditions of children and adults with intellectual disabilities in the four countries. We wanted to find examples of initiatives that had really succeeded in changing the lives of people with disabilities and also identify models of good practice that could be replicated. However, at an early stage it became obvious that it would be hard – and most probably impossible – to find such a common frame of reference.

A major problem was that any valid definition of a successful example had to take national, historical and cultural contexts into account. Living conditions of disabled people per se and changes in such living conditions depend, to a large extent, on contextual characteristics such as the national economical conditions, rights and obligations linked to the citizenship, cultural representations and customs etc. As a consequence processes of change affecting the living conditions of people with disabilities are likely to differ between countries. Any actions that prove effective in promoting change in one country are not necessarily going to be the most effective in another country. This had important consequences for our study.

Firstly, we came to the conclusion that our understanding of the processes of change and improvements in living conditions was better facilitated by in-depth studies of a few cases. The collection of rich contextual data through extensive studies of a few interesting projects was likely to be more helpful than broad comparisons of many different projects aimed at social change. Eventually, we decided to limit the study to three successful projects in each of the four countries. We gave priority to exploring the basic dynamics of change processes that had substantially improved the lives and conditions of people with intellectual disabilities. This meant we adopted a contextual definition of success, stressing outstanding changes within a specific context. Below, we will describe the contextual definition of success in more detail in terms of projects which are interesting because of their "transcending character".

Secondly, to investigate and understand the basic dynamics of change processes, it is necessary to study them in their own unique national and local contexts. This means that the study has been designed in two separate steps. Initially, projects that could illuminate the basic dynamics of successful change processes were studied in their own historical, national and cultural contexts. The findings of the national reports were drafted and discussed in national seminars. The comparative phase of the analysis was introduced in the second phase.

In short, the study starts with a rather *open exploratory* approach with the aim of increasing our understanding of successful projects in the four countries and identifying basic, important factors. The study ends with a more *comparative* approach exploring similarities and differences between the three examples (projects) analysed by each national team. Their aim was to sketch a theory of the dynamics of transcending change processes concerning the everyday lives of people with intellectual disabilities.

As a consequence of these modifications, the role of the national teams became more important. In fact, their roles changed from being primarily advisory to being a partner in designing the research methodology. The research strategy and design could be described as collaborative. It was gradually developed though propositions from the coordinating scientific advisers and through feed-back from the national coordinators and their teams. At some stages, the collaborative process was strengthened during intensive dialogue workshops where there was more room for the national teams to influence the design and the methods used in the study. To maintain a joint focus in the exploratory work in the various countries, and to make later comparisons possible, we adopted a semi-structured research design for the first exploratory phase of the study. More specifically, this meant the Swedish coordinating team presented draft guidelines/criteria for selection of successful projects. The national teams were then asked to develop operational national definitions of the proposed criteria in consultation with user groups. As a result the

proposed criteria were developed end redefined in each country; one additional criterion was even included. Additional funding was sought and granted by Sida to cover the costs of the collaborative research strategy and the joint workshops that became the main tool for consultations and coordination.

Thus, the methodology of the study was jointly developed with a series of dialogue workshops, where the national coordinators met with the Swedish coordinators and the two scientific advisors[4]. The dialogue workshops were organised at the following stages of the study:

- Finding a common frame of reference for the selection of successful change processes and developing national criteria for the selection (Montpellier, June 2004)
- Agreeing on the selection of cases and the methodology for data generation and analysis (Cape Town, January 2005)
- Finding a common frame of reference for the analysis (Stockholm, September 2005)
- Discussing and concluding the cross national analysis (Timisoara, September 2006)

Finding a common frame of reference for the choice of the successful projects
The study is designed to be rather open and sensitive to the approaches that the national research teams find most productive. However, it was critical to have a common basis for the selection of the cases to identify the differences and similarities in change processes within the four countries requires.

It was therefore agreed that
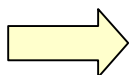
The examples of change processes to be selected for the case studies should be called *PROJECTS.*
A project is defined as a deliberate effort to achieve improvements in the living conditions of people with intellectual disabilities.

In the beginning of developing the collaborative strategy, there were extensive discussions on how to identify a "successful" project. There were many different views on what the criteria for success should be. As we have already mentioned, the definitions of what should be understood as successful also differs depending on the context. We finally agreed that a successful project must show evidence that it has had a great, positive impact on the lives of people with intellectual disabilities and be sustainable with local resources. To determine these features and qualities in more detail we established a common set of criteria:

1. The project must have had a substantial impact on the quality of life of people with intellectual disabilities.
This means that it must have had a positive impact on at least four out of eight Quality of Life (QoL) Domains to be selected (or had an exceptional impact on one of them). The impact must be verified by the people affected by the project, i.e. people

_____

[4] When we use the term "we" in this report it refers to this group of people.

with intellectual disabilities and their families. The IASSID Consensus Quality of Life Domains were used as a common frame of reference[5] to describe quality of life:

- **Emotional well-being:** safety, stable and predictable environments, positive feedback, self confidence/feeling of value, absence of physical/sexual abuse or bullying/teasing
- **Interpersonal relations:** affiliations, affection, intimacy, sex, friendships, interactions
- **Material well-being:** ownership, possessions, employment
- **Personal development:** education, rehabilitation, meaningful activities, assistive technology
- **Physical well-being:** health care, mobility, good health, nutrition,
- **Self-determination:** choices, personal control, decisions, personal goals, independence
- **Social inclusion:** welcoming social networks/support systems, integrated environments, participation
- **Rights:** privacy, ownership, absence of unfair discrimination, barrier free environments.

An important part of the collaborative strategy was for the national teams to provide local interpretations of these general concepts. This made the quality of life domains more precise and possible to use as selection criteria by the national teams. Based on interviews, with parent groups and groups of people with disabilities themselves, each national team documented practical, definitive examples of positive change in each of the eight domains relating to the local context of children and adults with intellectual disabilities. An instrument, listing the most important characteristics of the eight quality of life domains, was developed in each country. For example, it turned out that the domain "self determination" was not seen as a very important domain in the African and Indian contexts, where interdependence and family belonging sometimes were more important. An additional domain was created for the African context, namely **Interdependence or Ubuntu:** meaning the supportive mechanisms and mutuality within the home and within the broader community.[6]

2. The project must be sustainable.
It must:
- have been in operation for more than two years
- have less than 50 percent foreign resources/funding of its operations *or* have a trend of phasing out foreign funding/resources without affecting the quality of the project and/or the continued efforts to achieve change.

---

[5] The Reference Group examined different standardised instruments and more general points of departure that could be used for evaluating impact of the successful projects. Different tools have different benefits and disadvantages. As we were about to study relative changes in various cultural, political and economical settings, we came to the conclusion that we needed to use a tool that is flexible, easy to use and which is not relating to too detailed and context bound measurements of life conditions. We needed a qualitative instrument that was sensitive enough to capture different kinds of improvements on both individual and society levels from a user perspective. As indicated above, we finally developed the semi-structured, collaborative strategy with a set of commonly shared criteria and space for the national teams to explore the specific dynamics of the change processes in their own countries. While being aware that standardised quantitative instruments are usually preferred when making these types of comparative studies, we agreed that such instruments are not possible to use in this study. After a long discussion, the Reference Group decided to recommend the IASSID Consensus Quality of Life Indicators as more general guidelines in the choice of the successful projects.

[6] The culturally adapted QoL instruments developed in each country can be obtained from annika@nids.se

3. The project must have had a significant impact (substantial coverage).
It means that it must have a **significant impact** in the community (nationally or locally) – not only limited to service provision for a small group of individuals.

4. The projects must be interesting to study.
- Among those that fulfil the three first criteria, projects that seem to provide many interesting and useful lessons should be selected.
- They should differ in terms of organisation, activities and direction. National and local initiatives, government and NGO initiatives should all be considered. At least one of the projects should be implemented by an Inclusion International national member organisation or its affiliates.
- The projects should be innovative, exceptional and outstanding in their respective context or show extraordinary ability to cope with difficulties.

The gradual development of the definitions of what a successful project meant, also gave a special importance to this fourth criterion. Thus the final design of the whole study – with emphasis on the importance of the local context to understand success – led to a definition of a successful project as a project that "stood out" against the mainstream of existing services and living conditions for people with intellectual disabilities in the specific country. To some extent "outstanding" can be understood in terms of something new and innovative but also as a project that raises interest in the local context. We will come back to this later.

The national and common selection criteria were discussed and approved at a joint meeting of national coordinators, Swedish coordinators and scientific advisors in June 2004. The criteria developed through this collaborative process can be further elaborated and used to evaluate the success of any social change project aiming at improving the life conditions of a marginalised group in the four countries.

Selection of projects for case study
Invitations for nominations were distributed to organisations and networks known to the national teams. Both NGOs and government authorities were invited to nominate projects for consideration by the team. The nominations consisted of a rationale and an assessment in relation to the selection criteria. The reward for participation in the study was exposure in an international publication. It was also made clear to potential participants that a presentation of the edited nominations of all projects meeting the selection criteria would be published as a special appendix to the national reports.

Despite these efforts, it turned out that very few nominations were submitted. Some possible reasons for the limited response were the cumbersome self assessment tools and the orientation towards self nomination. Many projects have never described their results in terms of impact on quality of life or sustainability. They may have felt too much work was required to fill in the paperwork. Some projects did not want to expose themselves to the researchers and others did not see the benefit of participation. The teams had to work hard through their networks to identify projects that might fulfil the criteria and be interested to participate in the study. In the end the following nominations were received:
- India – 29 nominations
- Kenya – 22 nominations
- Romania – 15 nominations
- South Africa – 8 nominations

The nominations were scrutinised by the national teams (in South Africa by an independent panel of experts). Among those fulfilling the first three criteria, the most interesting projects demonstrating exceptional achievement in a difficult context or those that took an unusual or different approach were chosen. The decision was based on a consensus within the respective team. The projects and the rationale for the selection were documented and presented at a joint meeting of the national coordinators, the Swedish coordinators and scientific advisors in January 2005.

The final selection list surprised the international reference group. There were no national government initiatives or general human rights or advocacy initiatives. All projects selected were organisations rather than initiatives. All had a large component of service provision. Many of the selected projects had gone through difficult times and had some problematic sides along with the success. Most projects struggled with areas where they needed to improve - some more than others. A few of the projects are far from reaching international standards and expectations on inclusion and rights for people with disabilities. After the selection was completed some stakeholders approached the national team members saying they knew of better projects in the country. Some felt disappointed that they had not been informed about the possibility of participating.

All these observations were discussed at the joint meeting in January 2005. It was concluded that all projects selected were indeed seen as successful by the users and the national teams. The projects had all achieved something exceptional in their particular context. They were not selected because they were the most successful in their country, but because they proved able to change the lives of people with intellectual disabilities - despite everything. They all provided important and useful lessons on the factors that are important to succeed in initiating and maintaining processes of change. The fact that they were not perfect and were struggling with various shortcomings did not pose problems for the study but rather added an unexpected and interesting aspect. It also added credibility to the selection process that the projects were different from the expectations. It increased our curiosity to find out more about the projects and the factors leading to success.

After intense discussion, the national and Swedish coordinators and the scientific advisors agreed that all projects presented at the joint meeting in January 2005 could serve as useful examples for the case studies. However, it is important to remember that the projects selected are not necessarily exemplar projects in their country. They do all, however, fulfil our selection criteria as they "stand out" in their respective contexts and provide interesting and useful lessons.

From standardised indicators to case studies of the characteristics of transcendent projects
As mentioned above, the case studies, to a large extent, came to focus on the *transcending characteristics* of the developmental projects. This development of the study should be understood against the background of a need to find a definition sensitive enough to identify successful projects in all four countries. When we had given up our first efforts to try to find cross-culturally valid definitions of successful projects, we adopted what could be called a "*country relevant approach*", i.e. a way of assessing the impact of the project by comparing the achievements to a kind of "national, or even local, baseline".

The lesson learnt from the first attempts to try to find common denominators of improvement and success was that it was impossible to define valid cross-national indicators that were sensitive and general enough not to miss important advancements in the living conditions (attitudes, services and support, inclusion etc) of people with disabilities. The combination of the countries of India, Kenya, Romania and South Africa turned out to be a good test case illustrating how different living conditions could be for people with disabilities and, as a consequence, how different important improvements of living conditions and successful developmental projects could be. Our efforts to test the validity of standardised indicators like QoL instruments and the World Health organisation's classification of, for instance, participation of people with disabilities, also showed how little we actually know about key-factors contributing to improvements in living conditions for people with disabilities and about what characterises successful developmental projects. All these experiences contributed to our decision to refocus our study on exploring characteristics of successful projects, selected according to nationally defined, subjective and relative criteria. However, to fulfil the study's overall goal of making a comparative assessment of the selected developmental projects we also had to develop what we called "*sensitising definitions*" of successful projects.

Thus, the sensitising definitions used in the study can best be described in terms of the contribution of something new and outstanding from a specific project. By comparing project achievements to the "national or local baseline" it is possible to discover transcending characteristics of certain projects, which appear as especially interesting to people with in-depth local knowledge in the field. In a more philosophical context, the relation between the given (facticity) and transcendence have been analysed by, among others, Sartre (1960) in his book *Questions de méthodes*. Even though Sartre's analysis concerns personal developmental projects, his analysis is still interesting as a point of departure for our sensitising definition. Sartre's theoretical analysis of the project in terms of facticity and freedom also leads us to the important research tradition related to *Actions theory*. An important contribution of this theory is the analysis of how human action is framed by a certain space offered for a specific action in a specific situational setting or context. In fact, the space, or freedom, for transcendence depends on this action space and as we will see later, action space therefore becomes a key-concept in our understanding of the dynamics of change and improvement in the studied development projects.

Chapter 2 - Summaries of the national reports

The Indian report

Context
The term intellectual disability is often misconceived and misunderstood in India. Most people, including many professionals, still refer to it as 'mental retardation'; it is often used in the context of mental illness, lunacy or madness. This goes back to British rule and the Indian Lunacy Act 1912. Parents of people with intellectual disability have fought a prolonged and somewhat successful battle demanding that the government of independent India repeal this Act and recognise 'mental retardation' as a disability. It has taken many years, even for parents, to understand and accept that 'mental retardation' is a disability and not an illness.

The first national conference on "mental retardation" in 1966 voiced the idea that people with intellectual disability can contribute as members of society if they get the opportunity to participate in education, training, work and social activities. Prime Minister, Indira Gandhi, who inaugurated the conference, said that the parents of people with intellectual disability had an important role to play in their overall development and progress. The significant outcome of this conference was the parental awakening. Parents then organised themselves by forming associations, creating education facilities and crucially, demanding the government to treat people with intellectual disabilities as equal citizens.

Much has been achieved over the last 40 years with the repeal of the Indian Lunacy Act and a number of other significant legislative changes bringing about education, training and rehabilitation provision for people with intellectual disabilities. Inspired by the international initiatives on disability, such as the World Program of Action and the Standard Rules, the Indian government has adopted a number of new laws. The most important laws are the Persons with Disability [Equal Opportunities, Protection of rights, and full Participation] Act 1995, and the National Trust [for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities] Act 1999. Both laid the foundations for many different kinds of initiatives.

Many parents are now aware of the rights of their disabled children and are slowly coming out of the charity syndrome. Above all, the parents of people with intellectual and other developmental disabilities have come to accept that these conditions are going to remain essentially unchanged through the life span of their children, even into adulthood.

The three projects selected

GIMRC (Government Institute for Mentally Retarded Children) is located in Chandigarh, a union territory in the north of India. This is a government initiative providing educational and rehabilitation services for people with intellectual disabilities. It illustrates a change in quality of life from situations that are minimal and often degrading where individuals often have been left to 'God's mercy' to an improved situation where survival and basic needs are fulfilled through specifically set up services and facilities implemented by trained staff . It has gone through many ups and downs primarily due to conditions of discord and its effect on what may have been seen as a low priority area - a 'welfare' institution. GIMRC demonstrates what is possible within the framework and constraints of the government's bureaucracy in a very short time. The numbers that GIMRC is now providing support to have jumped to over 700 through the various programmes/facilities created within and outside its building premises. Over the years, there has also been a change of the type and variety of activities offered. No longer only custodial in nature, GIMRC's programmes range from academic to vocational, residential to home based. An exceptional feature is the kiosk, where young people with intellectual disabilities and their guardians work and are visible in the community. GIMRC also has insight to offer relating to sustainability and funding. Their experience shows that it is better to have more than one source of funding and not rely on just one source, even if it is the government, because funds may get diverted if there are more pressing societal concerns.

Vidyasagar is located in Chennai - Tamil Nadu in the south of India. This project is an organisation with a holistic and community based approach. They reach out to

people with multiple disabilities along with intellectual disabilities. Its initiation was inspired by the profound disability of the founder's son. They operate a 'no bar' philosophy. Its uniqueness is also in its strong community based rehabilitation component which has spread to several neighbouring states. Several thousands of individuals have benefited through this initiative. Leadership and timely decision making has played a big role in the success of the organisation. It has a more horizontal leadership style creating independent, yet coordinated units that can draw upon each other for strength without generating obstacles due to authority issues.

The way they live their belief in inclusion is another important reason why Vidyasagar succeeds. People with intellectual disabilities are not isolated from any 'category' of people, whether they are 'normal' or have some other disability. This has led to many creative and innovative strategies for raising visibility and awareness. Efforts at Vidyasagar combine scientific knowledge and skills with commitment and intuition. The focus is on the potential of the person without loosing sight of their specific and permanent disability. This involves bringing about change in both the physical and social environment by empowering parents and engaging in advocacy. They stress the community rehabilitation component. For Vidyasagar, inclusion begins 'at home', while simultaneously addressing the need for multiple care-givers, and the ongoing development of skills.

Mentaid is a parent driven day centre for people with intellectual disabilities located in Kolkata, West Bengal in the western part of India. It was initiated by a parent of a child with Down's syndrome, who was a professional in child development and education. With empowered parents, Mentaid has grown into an organisation founded on a strong partnership between parents and professionals. Programmes address the varied needs of people with intellectual disability from recreation to employment. Mentaid retains and nurtures the voice of intellectually disabled young people, without underestimating or degrading their ideas or feelings. It creates many opportunities for self expression, through the self-advocacy programme as well as the newsletter that many of the intellectually disabled people contribute articles to.

Mentaid has many strengths other organisations could learn from; empowered parents and families taking on professional roles and actively developing the activities of the project; exploring and using limited resources optimally; developing advocacy initiatives and networking with other organisations Activities of Mentaid are developed keeping in mind the cultural context. An example is the inclusion of siblings and extended families into their programme of activities. The parent – professional partnership continues to be an important element along with effective use of limited resources, and a vision that guides their progress. The parents' sense of ownership and belonging with Mentaid enables meaningful participation in a culturally relevant manner. The transparency of their efforts (willingness to easily share difficulties and successes) allows for sharing of the effort and enables Mentaid to develop. What also makes for success is their seeking an optimal balance between inclusion and special measures depending on the needs of the individual people and the degree of their disability. They then work out how to meet those needs with available resources and services within the community and Mentaid.

Common features and challenges
The following common factors were found when analysing the projects:

- Strong *leadership with a vision* shared with staff and parents. The project leader's role is critical role - their emotional strength, professional and personal experiences permeates to the service users.
- An emphasis on *capacity building* of all participants (staff, parents, participants etc)
- A *life span perspective* in developing facilities and services and a transparent and open *work orientation allows for* modifications and even transformation. For example, the physical structure by itself does not necessarily have an impact on the success of the project. It is rather the *innovativeness and the adaptations to the needs of the users* that are vital.
- Strong *networking* with other stakeholders in the community. Promoting *public visibility* of the project and the participants as well as *networking* and close partnerships with other organisations enable better living conditions for people with intellectual disability.
- *Generating funds in a variety of innovative ways*. Obtaining government funding does not necessarily ensure the project's long-term sustainability. Successful organisations develop innovative strategies, and many alternative sources for funds, enabling them to continue to develop and implement new ideas.
- Having a strong administrative and accounts audit, enables *efficient resource management* and is critical for the projects.
- The *involvement and vision of the staff* regarding the needs of people with intellectual disability determines, to some extent, the support the project gives to people with intellectually disability.
- The organisational structure: a *horizontal structure* is useful for the growth of the project if expansion and inclusion are the goals. People usually take the initiative to set up new activities when they have influence and *feel part of the organisation and its vision*.
- *Parent empowerment and involvement*. Projects, which encourage participation and involvement of parents and other family members, seem to be more successful.
- A strong belief in the abilities of people with intellectual disabilities and, the *conviction that they too have the right to a place in society*

These factors allow the organisations to undertake a variety of different activities which bring about positive change by lowering stigma, and ultimately move towards inclusion in all it forms.

The study found there are also challenges:
- Failing to recognise the need to have a second in charge to take on leadership roles
- Inability to recognise the changing needs and aspirations of people with intellectual disability
- Failing to recognise the need to have a combination of special measures and inclusion

The Kenyan report

Context

In much of Africa, the causes of disability are still largely misunderstood and shrouded in mystery. Myths have spawned widespread fear and stigma leading to hostility, discrimination and negative attitudes towards people with disabilities and their families.

Factors that hinder development in the disability field include for example:
- Ignorance and prevalent negative attitudes
- Endemic poverty among people with disabilities and their families,
- Inadequate social support systems,
- Poorly equipped and inaccessible health care facilities and services,
- Inadequate funding and lack of government policies and programmes,
- Limited numbers of professionals
- Uncoordinated and often competing initiatives among the disability fraternity

Despite these obstacles, Kenya has made some significant strides towards alleviating the difficulties of disabled people. After more than 10 years of advocacy efforts from national and international disability organisations, the Persons with Disabilities Act became law in 2003 and the government declared free primary education and instituted a policy of inclusion of children with disabilities in schools. These initiatives are in the process of being implemented nationwide. There are many problems and it is too soon to gauge the impact of these recent developments; however, anecdotal evidence suggests that the initiatives have had some effects and that it might lead to a better situation for people with disabilities in the future.

The four projects selected

Mathare Special Training Centre is a day centre for people with intellectual disabilities located in the vast Mathare slums in the eastern part of Nairobi. It was started in 1982 by parents of children with intellectual disabilities. The parents (mothers) needed a safe place to leave their children so that they could free themselves to look for food for their families. They managed to convince the teacher at the nearby school to provide space. Programmes at Mathare Special aim to equip learners with appropriate skills to enable them to participate more effectively within the family and in their community. The programmes include mobility, vocational, healthy living, language and communication, cognitive, and life skills. Mathare Special also has an outreach programme in the community and a parent association. From 1996 to 2000, the project was plunged into a period of decline. An evaluation by Inclusion International,[7] who have consistently supported the centre and observed it during periodic visits by their officials,[8] indicated a great concern. In their observations, they pointed out that Mathare Special has received much financial and other support but its performance remains dismal. Despite this, past students, families and community members reported that the project has brought about a lot of improvements in the lives of people with intellectual disabilities in an extremely poor and hostile environment. Families have been empowered and the community around Mathare Special learned that people with disabilities could contribute to society as other non-disabled people. They have learned to accept, appreciate, integrate and

---

[7] Mrs Marita Menpaa from Förbundet De Utvecklingsstördas Väl (FDUV) and Jyväskskylä Polytechnic - Evaluation report on trip at Mathare from 11th-30th October 2003
[8] Lars Bolander and Victor Wahlstrom

support them and their families. The education authorities are now paying the salaries of the teachers at Mathare Special.

Kaimosi Special School for the Intellectually Challenged is situated in Vihiga District which is an agricultural area in the Western Province of Kenya. Kaimosi School started in 1984 largely through the efforts of one local man, Moses S. Smith. His child, suffered trauma during birth and ended up with an intellectual disability that left him without speech. Kaimosi programmes include mobility skills, vocational skills, healthy living skills, life skills, language and mathematics skills, communication skills, pre-vocational and vocational skills. These programmes aim at equipping the students with activities of daily living skills. They build on each student's strengths and work to develop them. Some children attend mainstream classes through the support of Kaimosi. Community awareness has been created through drama and plays, and through participation in games and sports. Kaimosi school has equipped students with skills that some have used to improve their quality of life considerably. Quite a number of them have been able to get married, which is an extraordinary achievement. Members of the community have come to appreciate the good work that the school is doing and are continuing to send their children there.   The community is providing both moral and material support to enable it to continue to exist. However, government support is still limited.

St. Catherine's Primary and Technical/Vocational Institute for the Intellectually Disabled, Butula is a government school initiated by a catholic priest with a vision. The programmes at St. Catherine's are intensive and designed to prepare students to be integrated back into their communities. Students are taught key skills in daily living, reading and writing. Pre-vocational classes for boys and girls from age 15, introduce them to practical work related to the home environment. These include poultry keeping, animal husbandry, preparing and maintaining a tree nursery. Vocational classes equip students with trade skills such as carpentry and joinery, agriculture, knitting, sewing and weaving to prepare them for paid employment. An interesting and innovative element is the Independence Hut where students practice common chores typical of any homestead in the village. From the Independence Hut, students move to the sheltered farms, before going on home-based programmes. The design and decision to involve families in home-based programmes has promoted their success. The families have learned how to run income-generating projects from the school through training and supporting their children. Their lives have been further enriched with the on-going support services extended to the families enabling them to implement the home-based programmes successfully.

Mother Theresa CBR project is located in a local primary school just on the border town of Namanga (Kenya/Tanzania border), in the dry savannah land that is typical for the undulating plains, home to the world famous Maasai people. The community based rehabilitation project was the brainchild of Mr. Muhindi and other parents who were drawn together by a common need for activities and training close to their home for their children with disabilities. The group have succeeded in raising awareness of disability among the community members and enhanced their profile as advocates for children with disabilities. Through its campaigns, Mother Theresa CBR group members identified children with disabilities in the community and persuaded their parents to send them to the school. This is an important achievement in a context where there is extreme stigma attached to disability. Parents of children with disabilities are increasingly seeking early intervention for their children and children with disabilities have become visible in the community.

Common features and challenges
The following common factors were found when analysing the projects:

- In all cases but St Catherine's Butula, *parents were the initiators* of the projects – the *vision carriers*. In Butula, a priest with the means and the vision started the project. The parents teamed up with professionals to realise their dream. The parents were driven by inspiration from other projects, personal initiative, resilience, creativity and self-sacrifice. Many parents took great personal risks when challenging prevailing attitudes and norms in their communities.
- The quality and strength of *interaction* between the project leader and his/her staff members, the student and his/her family, the local authorities and the communities was important for success. Where the relationships between the parties were strong, and they collaborated and shared the ideas and visions, achievements were great. The reverse happened as in the case of Mathare where the deteriorating relations between school, parents, communities, led to negative outputs – reduced enrolment, stalling of activities, etc.
- Programmes that were *responsive to the needs of the participants* and designed to achieve definite and positive outcomes led to the improvement of their quality of life. Programmes designed to strengthen weak areas and enhance strengths, even as students acquired new, practical skills to use at home and in the community, led to improvements in QoL. Involving the family of the people with a disability in the programmes enhances the long term positive effects.
- Another important factor that was responsible for bringing about change at the centre was the *availability and quality of allies, networks or partners* to share the vision with and work together. These could be individuals, organisations or even government and civic departments. Networking between the family, service providers, (social workers, community health workers, teachers), community leaders and donors seems be essential for success and sustainability of results.
- *Involving the people with disabilities in the activities of the family and community* promotes acceptance and breaks down barriers. This helps develop their social skills, self-esteem, interpersonal relations, personal development, physical well-being, self determination and realisation of their rights. At the same time, community involvement contributes to the development of positive attitudes towards people with disabilities and their families.
- The *political environment and the global trends* seem to have created a positive environment for the projects. There was heightened awareness of disability issues, political goodwill and the time was right for finding support for disability projects internationally and nationally. At the same time, some parents were beginning to examine their circumstances and explore ways of improving their own situations
- The findings indicated that a *strong, focused leadership* that gives direction and is willing to guide the team in the activities was a factor in facilitating and promoting development.
- *Empathy* with the students and their families was another ingredient that seemed to foster achievement. The staff exhibited a caring attitude towards the children enabling them to enjoy learning and acquire skills. Many of them had *personal encounters with disability* and had made a, "Conscious choice to serve the disabled who are also the less fortunate in society", as one

respondent put it. Positive attitudes and practices towards people with disabilities by staff is essential to improve their quality of life as it promotes acceptance, the acquisition of social skills, diminishes isolation and stigma.

The challenges facing the projects are:
- Lack of adequate knowledge and understanding of disability
- Prevalence of negative attitudes
- Weak parental support and lack of parents' associations
- Lack of finances, dependence on one donor
- Weak networks and weak links with authorities
- Lack of capacity and professional support

The Romanian Report

Context
Under the communist regime people with disabilities were hidden and excluded from 'normal' society and treated as second class citizens. They were sent to residential centres, like special schools, vocational homes and psychiatric establishments. Public opinion – and even staff in these centres – did not accept them as normal members of society. Parents tried to have their children enrolled in ordinary schools or employed in ordinary economic activities to escape the closed world in an institution.

The situation changed radically for people with disabilities – like everything else in Romania – after 1989. Several government organisations are now responsible for people with disabilities: State Secretary for Persons with Handicap (SSPH), National Agency for Child Protection and Adoption (ANPCA), Ministry of Health and Family (MHF), Ministry of Labor and Social Solidarity (MMSS), Ministry of Education and Research (MEC). As a result of NGO and parent organisations' efforts, many children's community services have been developed in the last few years, such as inclusive educational programmes, family counselling and support and respite care and day centres. EU funding and from other donors has helped with the process of de-institutionalisation of children. Over the last 10 years less than half of children with disabilities are now in institutions. The employment situation has also improved considerably. A new bill in parliament says professional training for people with disabilities will have state funding. All workplaces in the scheme would have to have four people with disabilities for every 75 employees.

However, a recent EU report stated that the situation for people with disabilities in Romania remains a weak area. Disabled children and adults still face considerable hostility and exclusion in Romania because of their disability. Parents are pressured by traditional norms into hiding their disabled children away. Even staff in the projects included in this study have experienced aggression and ostracism; the Lacrima project in Bistrita was set on fire. Around 14 000 people are still living in institutions in Romania. A majority of them could be people with intellectual disabilities, but no-body knows for sure due to lack of statistics and definition of intellectual disability. There are also around 150 special schools for children with intellectual disabilities in Romania for over 20,000 children. These schools use separate curricula and programmes developed by the Ministry of Education.

The three projects selected
Lacrima Special School in Bistrita is the only public school in Romania specially designed for pupils with more severe intellectual disabilities. The pupils at Lacrima are children that would normally face exclusion from any form of education and most often confined in closed state institutions or in their homes. It is also one of the few schools established by a parents' association, and even directed by a parent of a disabled child.
The Lacrima Special School was formally established in 1995. It was set up by a group of parents. Later it gained approval and finance from the local government and organised within the formal educational structure under the Ministry of Education. Lacrima Special School is also unique in its pedagogical setup as it challenges the traditional model and curriculum for special schools in Romania. The basic philosophy is that each child is unique and needs stimulation and support that

reflects this uniqueness. And the stimulus and support must be emotional as well as intellectual. Or, as the director puts it: "*I would like to find for each pupil his sense in life. I found out that these children also need our love maybe more than the others*". To be able to provide this, the school has developed a multitude of ways and means, such as colourful and pictorial decorations, well equipped playgrounds, a variety of different animals etc. As the school even provides respite care from eight in the morning till six in the afternoon, children have a lot of time to utilise these resources.

The Arnsberg project is a rehabilitation centre. It aims to improve the physical, emotional and intellectual functioning of children with disabilities. The centre focuses primarily on impairments, and not so much on disabilities which rather limits its scope even for a rehabilitation centre. Still, it is an important aspect and one most often overlooked for this group of children in Romania. It is a modern, well equipped centre with highly motivated staff dedicated to providing the best services possible to each individual child, within its scope of operation. The Arnsberg centre is a unique project within the Romanian context, not only because of its material and professional qualities but also because of the ways in which children and parents alike are met and treated on an individual bases.

Although the Arnsberg centre is a medically oriented institution, it has largely been able to break away from the traditional medical perception of disability. Instead, it has introduced a more modern and sympathetic treatment of children with disabilities with professionalism and respect. Arnsberg centre is a good example of a modern Romanian institution where residential care is very limited and very comfortable; friendly attitudes have replaced formal and distant treatment of the service users. In fact we did not find any institutional abuse towards the children. We saw this as an example of good practice in its field.

Pentru Voi is one of the best day centres for adults with intellectual disabilities in Romania, enjoying an international reputation. A parent association set it up and today it is currently headed by a parent, who is a very strong leadership figure. Pentru Voi has a wide range of services for people with intellectual disabilities including day services, residential services, respite services, community support, self advocacy, training and publishing. These services have been developed in response to service users' needs. Some of the services were developed for the first time in Romania such as self advocacy, the protected housing and independent living network, the bakery (a new concept with educational, community service, and self sustaining functions), supported employment, respite services for adults and social activities. The vision, philosophy and values of Pentru Voi are characterised by respect towards service users and their families, empathy and unconditional support without making demands or judgments.

 Pentru Voi has been a pioneer in the implementation of an inclusive approach to intellectual disabilities. Its ethical codes are published on the internet for others to see and follow. The organisation has undertaken a number of local campaigns for increasing the community acceptance of people with disabilities. This has had a significant impact on the citizens of Timisoara. Pentru Voi has also actively influenced national legislation and policy. Pentru Voi led the first national strategy for disabled people. They also created a coalition of NGOs and a partnership with state institutions. Many of the laws were adopted after Pentru Voi developed the services, thus serving as national role models.

Pentru Voi also has a unique model of public-private partnership. The centre is a public institution where salaries and running expenses are financed by the city council while the premises belong to the Pentru Voi Foundation. The activities are planned and monitored by the Foundation. It is rare in Romania for city hall to not impose their rules on an institution it finances. But with Pentru Voi, the city council finances the Foundation's initiatives on its terms. Pentru Voi has a variety of external donors which increases its autonomy. Ten different donors have assisted the Foundation to build a strong financial base, including ownership of buildings, apartments, cars and land. All these properties make the Foundation a very important and strong partner in negotiations with state representatives. Another powerful aspect is its governance with influential and well-connected board members from the political and business world.

Common features and challenges
The following common factors were found when analysing the projects:

- *The leadership and management:* Two directors are parents of children with disabilities. In addition, they are well qualified and according to testimonies had the ability to use their qualifications for the benefit of the projects. The director of Arnsberg centre was not a parent, but his contribution is similar to the two other directors. Successful leadership is about having a vision and an ability to communicate these visions to others. Courage to pursue the vision, to convince donors, to communicate the visions to staff and motivate them to work in the same direction are crucial factors in this success.

- *Sympathy* and *identification* with service users from *managers* and *staff*: The values, enthusiasm and dedication observed among staff was strikingly common across all projects; not something we expected or felt is commonplace. The relationship between care givers and service users in these projects is characterised by mutual respect, personal identification and friendship, substantially reducing the traditional gap between "us" and "them". The analysis even suggests that there is a type of natural selection of staff operating in these projects. Staff members who do not easily understand and feel empathy for service users find it difficult to work in these projects and ultimately resign.

- *The parents:* An important source of the empathy and identification is the parents themselves. With the advent of a new political era, they saw possibilities for making a better future for their children. With strong parental involvement, not only in the project's initiation or establishment, but also in its management, this sympathy and identification with service users was easily communicated to staff. Thus, parental involvement is not only important in the establishment of the projects, but also as the prime source of transferring values.

- Another feature across projects is *exposure and community involvement*: One of the first things the manager of the Arnsberg centre did was to dismantle the perimeter walls. They invited the public to "open days" and exposed their activities and service users through the media. Furthermore, they introduced social activities such as going to the city for a pizza or going to the cinema. At Pentru Voi, neighbours, friends of staff and the general public take part in activities, parties, exhibitions etc. Pentru Voi has a high public profile, often on view in the media and referred to as a national model. Lacrima has been successful in mediation through media, especially through the weekly TV-show dedicated to the association. This *exposure* is an important part of an *inclusive strategy*, insisting that people who have been hidden away, whether

in their homes or in public institutions, have the same right as anybody else to access and to be part of the community as anybody else.

- *Networks* play an important role in providing examples, images and experiences of inclusion. All three projects have extensive contacts with external networks tapping economic resources, energy and ideas. Parental networks are also important as they provide a generalised notion of *what's best for our children*.

The challenges facing the projects were:
- The survival of any innovative movement depends on successful succession planning.
- It is alarming that the active involvement of parents seems to be fading in the projects studied. This needs to be overcome, by creating more defined roles for parents, through employment, participation on governing bodies, strategic planning groups and think tanks.

The South African report

Context
Over the last 20 years there have been substantial challenges to dominant perceptions of and attitudes towards people with disabilities in South Africa. The government's policy has been to recognise, understand and address disability issues as a human rights and development issue. The principles of non-discrimination and equity are entrenched in the constitution.

Under the apartheid regime, people with disabilities and their families experienced exclusion. This was due to the political and economic inequalities of the apartheid system; social attitudes which perpetuated stereotypes of disabled people as dependent; and a discriminatory and weak legislative framework which sanctioned and reinforced exclusion. Poverty, unemployment and social isolation are the key forms of exclusion that disadvantage disabled people.

Despite moves towards a social model of disability and an aspiration to address disability as a human rights issue, legislation continues to contribute to the social exclusion of people with disabilities. Although the rights of people with disabilities are enshrined in the Constitution, there is, as yet, no disability specific legislation.

Despite the availability of social security benefits to people with disabilities, the roll out of such service delivery remains problematic. Most disabled children in rural areas do not have a birth certificate- a requirement for social security benefits. Consequently, the birth of a disabled child often places heavy demands on family morale, thrusting it deeper into poverty. This not only means that there is a higher proportion of disabled people amongst the very poor, but also an increase in families living in poverty as a result of disability.

The three projects selected
Astra Centre is located at the foot of Table Mountain within an affluent suburban/central business district. The project provides sheltered employment to sixty Jewish men and women with varying degrees of intellectual and psychiatric disabilities and illnesses. The main aim is to develop the potential of people with disabilities to add value to their lives through meaningful employment. In addressing this aim, Astra develops and provides individualised programmes and services by utilising an interdisciplinary approach based on Jewish principles and values. The specific focus of the programmes is on individual strengths, needs, abilities, interests and desires. They provide sheltered employment as well as supported employment in the open market.

The success of Astra is the way they focus on the abilities of each service user; identifying creative means to explore and develop their potential. They build staff and service users' capabilities to work well together. They appoint staff who have a passion, are willing to become team players and develop good interpersonal relationships with service users. Astra also finds creative opportunities to involve the local community and so generate awareness of people with intellectual disabilities. Examples of this are the coffee shop and the gift shop established in the rather prosperous Cape Town suburb. Finally, Astra has managed to create a reliable network base and shown ability to be proactive at developing transforming activities according to new government policies.

Happy Home is a self-help project for parents of children with disabilities. It is situated in a rural area of the Eastern Cape in South Africa. The area has high levels of poverty and unemployment. The project was brought about through empowerment programmes offered by Disabled Children Action Group, the national parent organisation and the initiative of a committed individual in the community. She took on an important leadership role and is still heading the project. The main objective of the project is to assist children with moderate disabilities to access education. The project offers programmes such as early childhood development, stimulation and education for children with varying degrees of disabilities; business skills training for disabled young people; income-generating skills training for mothers and hostel facilities. The project also has outreach empowerment and development programmes in the villages and districts.

One of the outstanding features of Happy Home is its ability to overcome challenges in a poor and marginalised environment. Through innovative methods, such as prayer gatherings, night vigils and passive resistance, the project generates awareness and opposes injustices. They have managed to access the social benefits stipulated in the South African legislation. The identification of common problems and the response to locally experienced needs raised the sympathy, interest and involvement of parents as well as the surrounding community. The project is respected and supported by well-known members of the community, including Nelson Mandela. It has succeeded in bringing about changes in the lives of families, beyond the direct participants in the project. It has close relationships and interaction with the community and is flexibility and responsive to people's needs. It has also managed to motivate and retain many volunteers from the community, who share the values of "Ubuntu" and have respect and understanding of the rights of children with disabilities.

Whizz Kidz special needs centre is situated in Pinetown, west of Durban city, within the province of KwaZulu-Natal. The project offers educational and life skills programmes geared towards children and young people with severe disabilities. The project has various activities addressing the specific needs of the children. The objective of the project is to provide an effective educational programme responding to the specific needs of each student regardless of cultural background, ability and language. The project has instilled an ethos that each child with a disability has the right to participate in childhood and family life, and have opportunities for future learning. The director (who resigned her permanent post at a special school for severely and multiple disabled children rejected by the formal educational system) founded the project in 2001. Whizz Kidz is a project truly driven by her dynamic leadership style. The project is supported and strengthened by the governance structures, its vast networks and the services it provides. The project, despite its relatively young age, has shown itself to be a very vibrant and interesting project for the development of children with severe disabilities. Other outstanding features are the well trained and highly committed staff, the on-going training for staff and parents and the innovative, dynamic, constantly developing approaches and methods. The project has also demonstrated ability to bring diverse networks, expertise and resources to their assistance.

Common features and challenges
The following common factors were found when analysing the projects:

- All demonstrated *positive attitudes and mindsets with a focus on the person's ability and not their disability*. The importance of an accommodating environment based on respect, understanding and care was clear. All projects were committed to the social model of disability.
- The projects *responded to the needs of the service users* and developed activities according to their needs and the opportunities arising from their particular contexts. *Parental involvement was a key* feature in all projects.
- Social and human *rights activism and the political transformation* in South Africa all influenced the projects. A common cultural value base derived from the surrounding community, i.e. Ubuntu and the Jewish community enhance two of the projects.
- They all had a *leadership style that was dynamic and sensitive to contextual characteristics*, reflected relevant personal values and understood basic needs of the community facilitating a shared vision and commitment. This led to *staff commitment* and a *solid value base* for the project.
- The projects *adapted to their particular contexts* and used opportunities available in their networks and communities. They acknowledged culturally specific individual and common values and their communities accepted and supported the projects.
- They were involved in *advocacy and awareness campaigns* and created *independence and empowerment* with the help of job creation opportunities and skills training
- They had *good management practices* and were able to *establish and maintain reliable networks* to sustain their operations. They could combine the value base with professionalism, be strategic in the planning and development of the project, and keep updated on matters relating to, for example, government policy and legislative developments.
- They all used *capacity building* and various training activities as a key element to continue the development and empowerment of service users, parents and staff.
- *Creativity, innovativeness, effectiveness, braveness / risk taking and persistence* seemed to be driving forces.

The challenges facing the projects were:
- Leadership succession
- Difficulties generating a diverse and sustainable funding base
- Dissatisfaction with the slow implementation of government programmes and support to projects. Difficulties building good, mutually beneficial relations with government structures.
- Capacity and energy to expand activities, increase coverage and maintain networks and relationships is decreasing.

Chapter 3 - Cross national analysis

Before presenting our comparative analysis in detail, we will first give an overview of the methodology used in the cross national, comparative study and present the analysis in brief.

Cross-national comparison

The study presented in this report is rather unique as it includes no less than 13 individual case-studies, in four different countries. The methodology guiding the case-studies is already described earlier in this report. It is necessary however, to touch upon a few methodological aspects from the case-studies as we move from the national to cross-national analysis.

The design of the case-studies was developed through a collaborative process. The main framework of the study, such as the choice of countries and the number of projects to be studied was a given from the start. However, almost all methodological decisions were made or challenged during the process. For instance, even though the main criteria for selecting the cases were decided upon beforehand (see chapter 1), they were substantially altered as it became all too apparent they needed to be culturally validated in each country.

One selection criterion was that projects should be regarded as successful in improving the quality of life of people with intellectual disability. Since the recruitment of projects was based on self-nomination and from written accounts from applicants, the selected projects would not necessarily be the very best projects of its kind in their country. That was neither the intention nor necessary for the validity of the study since our objective was not to evaluate the projects as such, but to study processes contributing to positive change. It was sufficient that the project met a certain set of criteria. Thus, all projects selected should contain elements of positive change that made them *stand out* from the ordinary and consequently *interesting* to study. Earlier we referred to this criterion as a sensitising definition of positive change in terms of living conditions. The basic meaning was the *transcending character* of the projects and it was often precisely these characteristics that made the selected projects outstanding in their own national context. What we mean by *'transcending'* will be clarified in the discussion of the theoretical project, below.

The more detailed design for the case-studies was developed during the trans-national meetings, where the coordinator/researcher from each country participated. We agreed upon dividing the case-study into two parts.

Part one was descriptive. All relevant aspects of the project were thoroughly described, based on extensive interviews and observation, and ended with highlighting the *outstanding* elements of the projects. The description was not a simple mapping of factual information, but rather closer to what Geertz (1973) defined as "*thick description*", in that it tries to grasp the "stratified hierarchy of meaningful structures" (ibid: 7) apparent in the projects.

In the second part, defined as the "archaeology" of the project, the sources of these outstanding elements were traced back in time: How did it come about? What were the historic circumstances and the discursive contexts under which these elements emerged? What were the favourable conditions under which the projects developed into what they became?

In analysing the data, an interpretive methodology was applied in each country – actual procedures varied to some extent depending on the personal style of each researcher. In all countries, data was organised to allow for a systematic investigation of the themes and for systematic comparison both within and across cases. There was an ongoing dialogue between national coordinators and the scientific advisors through out the whole analysis. This allowed coordinators to discuss ideas and possibilities and create – with sensitivity to cultural and contextual differences – the possibilities for cross-national comparisons. This provided the same degree of rigour in the analysis in all countries and ensured a sufficient flexibility to account for distinctive cultural characteristics. Sometimes the scientific advisors introduced questions to the data that was important in one country, but never in such a way that it skewed the analysis in a certain direction.

The major part of the cross-national analysis is based on the national reports and the 13 case reports, but like all qualitative inquiries, analysis is an ongoing process. It is inevitable not to think in comparative terms when following the analysis in different countries. At the last joint meeting of coordinators and scientific advisors we had a discussion about commonalities and differences across countries, based on the themes defined in each country. The patterns revealed through this discussion (described later in this report) form an important basis for the cross-national analysis. It gives a thematic overview of the central aspects in all or most countries and those which appear to be more culturally specific. However, a cross-national analysis of this kind requires a theoretical framework allowing for a conceptualisation of the relationships between thematic similarities and differences on the one hand and the cultural contexts which ground these themes on the other.

Our analysis of the data presented in the descriptive archaeologies of the selected projects is based on a combination of two approaches:

- A systematic investigation of the data for themes with constant comparison both within and between national projects. Also, systematically relating themes to each other, searching for relationship patterns, with a special focus on transcending features, favourable conditions, transcending forces and outstanding activities. This mainly applies to the national case-studies.
- An interpretative analysis, linking the empirical patterns together in an understanding of the outstanding/transcending characteristics of the projects.

Interpretation – a way of linking the empirical observations in the four countries into a meaningful understanding
In the initial comparative approach of the national studies, a number of important themes of improvement, threat and transcendence were identified. Some were highly significant in the development of the selected projects. In the national reports attempts were made to understand each specific combination of themes as a whole, i.e. themes have been linked together in patterns forming more general themes and patterns describing processes of, for example, empowering parents and project management to make the development of the project understandable.

In our cross-national analysis we started by summarising the national thematic profiles and patterns of important themes to identify more general themes and patterns. Thus we could reach a deeper and more comprehensive *understanding* of the crucial conditions for transcending projects. In a somewhat simplified way, this phase of the main comparative analysis can be described as fleshing out the gaps

between the empirically grounded themes and patterns by a meaningful, theoretical reasoning that links the key-observations together and makes them understandable as a whole.

In this kind of interpretative analysis we focus on commonalities and highlight concepts and processes of general relevance to all the projects. Here, it is unavoidable that some relevant aspects of the local projects are lost. Theoretical comparison at a cross-national level of analysis always means giving up some of the contextual flavours of the local projects to learn more generally valid lessons. In this case, what makes projects transcending and outstanding and what routinises them and make them loose their power. These lessons can be used in designing and understanding future projects. However, one should be aware that the theoretical links introduced to make sense of the empirical observations also deprive them of some of their local authenticity and validity.

The theoretical frameworks introduced below are founded on the findings in the national reports and our final comparative analysis. However, this does not mean that our theoretical concepts have emerged out of data all by themselves. We also based our analysis on already existing knowledge (our own and others). We had a pre-understanding that helped us interpret the data. In the research process new understanding always builds on earlier understanding. In fact, this is the nature of the cumulativity of knowledge in the human science tradition we have been inspired by.

The interpretive research tradition is rich but also diverse and sometimes hard to summarise. Several rather different traditions are possible to identify. Our way of interpreting the common themes and patterns of themes links on to a methodological work carried out in the Scandinavian countries during last 40 years with inspiration from the hermeneutical and phenomenological traditions (Trankell 1973, Løcken 1965, Ödman 2007, Gustavsson & Bergström 2004).

Analysis in brief
We start with descriptive summaries of the developmental projects. Later, we discuss the findings in more detail. In the second section of the analysis we move beyond description and sketch a theory of a transcending project. We conclude with a short summary of the basic results in the cross-national analysis.

Description of basic aspects of the developmental projects
The cross-national comparative analysis raises new and different questions to the national studies. Even if each project has its own local and national context with its own questions, it was necessary, in the comparative analysis, to go back to the case studies and ask new types of questions. One such question concerns the overall picture of the projects. Below we have looked at a few descriptive aspects of the projects and summarised them in table 1.

Table 1: Description of basic aspects of the projects

Name:	Location	Main activity	Participants [1]	Age	Basic funding	Networks	Initiator
Astra	Urban	Employment	60	54	Private	Jewish Similar act.	Doctor
Happy Home	Rural	Education	77	8	Private	Mother org Commun.	Parents
Wizz Kidz	Urban	Education	40	5	Private	Similar act.	Teacher
Mathare	Urban	Education	175	24	Publ/priv	Commun.	Parents
Kaimosi	Rural	Education	142	25	Public	Commun. Similar act	Parents
St Catherine	Rural	Education Employment	238	26	Publ/priv	Cat church	Priest
Mother Theresa	Rural	CBR Education	20*	3	Private	Parents	Parents
Pentru Voi	Urban	Multi	125	10	Publ/priv	Int. donors Incl. intern.	Parents
Arnsberg	Urban	Rehabilitation	200	3	Public	Int. donors Profession.	Public
Lacrima	Urban	Education	74	12	Public	Int. donors Incl. intern.	Parents
GIMRC	Urban	Multi	250	8**	Public	Profession.	Doctor
Vidyasagar	Urban	Multi	1800	21	Private	Gov. org. Int. org Profession.	Parents
Mentaid	Urban	Multi	80	20	Private	Int. donors Incl. inter.	Parents

[1] The numbers refer to the participants directly involved in the project at the time of the study. It should be noted that the total number of people reached is much larger as the projects have operated for many years. Also most projects have contributed to changes in attitudes and practices that have affected people with intellectual disabilities beyond the direct participants
*) They also reach out to other (potential) children and families but the number is difficult to estimate.
**) The history of the centre goes back to 1964, but was more or less re-established in 1998 after 10 years of decline.

The overall picture of the projects was somewhat different than expected, due mainly to the selection criteria. The sustainability criteria (projects should have been in operation for at least two years) with less then 50 percent foreign funding implied that most projects nominated were already well established as more or less permanent organisations or facilities. As revealed in table 1, the majority of the projects have more than ten years of operation, the oldest being the Jewish project Astra in Cape Town going back more than 50 years. Another characteristic feature is that all projects are mainly focussed on service provision, perhaps with the exception of Mother Theresa which is a group of parents doing mainly awareness raising and fundraising for a special unit at the local school. No disability organisations, groups of activists, government policy initiatives or university programmes (to mention a few alternatives) are selected nor nominated, as far as we know. This is probably not because potential candidates do not exist, but perhaps because the impact on people's quality of life is easier to justify for organisations offering actual services, especially in countries where the availability of good services is very limited. The impact on quality of life should even be *substantial,* which might be extremely difficult for other types of projects to justify. It might have been interesting to have a broader scope of projects. On the other hand the projects chosen do represent a rich selection of interesting cases, all with their specific and outstanding features, making a limited variation in some respects rather an advantage for comparative purposes.

Most of the projects are located in urban areas (9 out of 13). It might be easier to form a community or collective force strong enough to establish such projects in urban areas, as compared to rural areas. In rural areas where the population is less dense it could be more difficult for parents to meet. Stigma also makes it more difficult to form associations of disabled people in rural areas where everyone knows each other, than in cities where social bonds develop more from networks than localities. Furthermore, resources are easier to find and exposure to new ideas is more common in urban areas.

The number of people directly participating in the projects at the time of the study varied considerably, from 40 children at Wizz Kidz, to 1800 at Vidyasagar. Concerning funding, we see that very few projects rest solely on private donors, but the amount of public funding varies substantially. All projects are connected to networks, be it local communities, religious communities or more professional networks, quite often all of the three at the same time. Some of the projects, especially the schools, are linked to networks of other similar projects, while some projects have developed strong and important networks abroad.

As we see, eight out of 13 projects were initiated by parents. Some of these parents were also professionals. Two projects were started by medical doctors, one by a teacher, one by a priest and one project, Arnsberg centre, was initiated by public authorities. We will refer back to these patterns several times during the report.

Beyond description
The national reports constitute one point of departure for our comparative analysis. In the concluding analyses of the national reports, a number of themes are highlighted as essential for the understanding of the transcending characteristics of the case studies in each country. At the joint coordination workshop held after the completion of the national studies these themes and conclusions formed the basis for discussions around possible cross-national patterns appearing in all countries.

One conclusion was there were far more similarities between the countries than we had expected or dared to hope for. We were concerned that possibly the similarities had been forced on the study by the design or by the scientific advisers. A further examination showed that the common themes were well grounded in the national cases, even though they appeared in quite different forms and combinations. In the national analyses themes and categories were used only if, and where, they made sense in the understanding of local projects.

As is illustrated in table 2 (below), the general themes and sub-themes appear to a different extent and in different configurations in the national reports. The names given to the general themes also vary, as do the proposals concerning how the relationships between the themes can be understood. A simple addition of the themes which emerged in the national reports presents three general themes and the following number of sub-themes:

Table 2: Common themes and sub-themes in the national case studies

Common strategies used	Common characteristics	Common basic factors
Interdependence, community involvement and participation	Creativity and innovativeness	Involvement of parents who desire change
Networking and use of allies and partnerships	Shared value base - a strong belief that people with intellectual disabilities have a right to be part of society	Leadership with a strong vision, inspires others, establishes and maintains networks
Advocacy and awareness raising	Effectiveness	Staff commitment, empathy and satisfaction
Exposure and visibility in community and society at large	Braveness/risk taking	Good management and professionalism
Constant capacity building of participants, parents and staff	Persistence, never giving up despite difficulties, trying new avenues	Community acceptance
Emancipation and self representation	Flexibility of activities according to changing needs and opportunities	Supportive local (and sometimes also external) networks

Even though the themes of the national reports have much in common, they also appear in different ways forming parts of different patterns and contexts of meaning. When similar patterns, themes and incidents were compared across countries it became evident they did not always form the unity that the conceptualisation indicated. In the same way, what appeared as differences on one level could be understood as belonging to the same phenomenon on a more theoretical level. To make true comparisons possible and to identify true cross-national patterns we were forced to "go behind" the national reports again to try to understand the themes, incidents and reported processes on a more theoretical level. We needed a conceptual framework that patterns and phenomena appearing in different contexts could relate to. This interpretative analysis can be described as a gradual hypothesis-validation process. Going back and forth between data, the national reports, existing

theories in the relevant fields and new cross-national theoretical hypothesis, we could gradually build a theoretical understanding of the common characteristics of the transcending development projects.

The theoretical project
In-depth studies of the projects revealed an initial confusion between the projects of (cases nominated and selected for the national studies) and a more theoretical idea of the innovative perspectives and activities carried out with the concrete, practical projects. During our joint coordination workshops, we sometimes talked about this theoretical idea of the "theoretical project" or "the projects within the project". One important result of the cross-national comparison was the development of a sketch of this theoretical project and its three basic dimensions; perspective, activity and routinisation, as illustrated in figure 1.
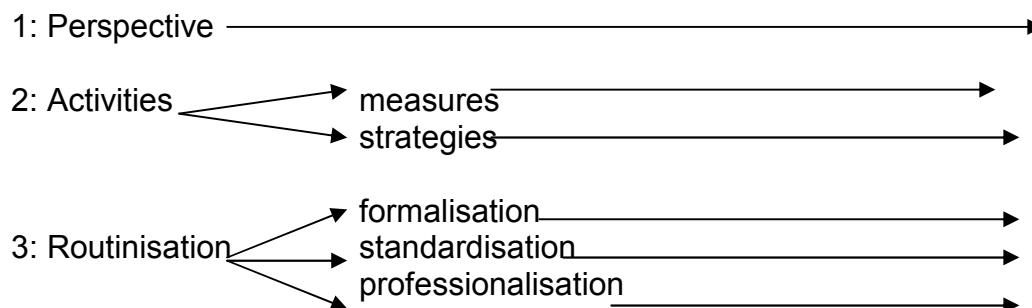
1: Perspective

2: Activities —— measures
—— strategies

3: Routinisation —— formalisation
—— standardisation
—— professionalisation

Figure 1: The three theoretical dimensions of the project

All initiatives were based on some kind of local *perspective* maintained by key-actors in the projects. These perspectives were, in turn, based on particular experiences held by people in special positions. The most important being parents with personal experience living with disability and some people employed in the disability services with a deep understanding of the difficult living conditions of people with a disability. In one way or another, these perspectives could often be characterised as *counter* perspectives, as they constituted alternatives to the ways opportunities and rights of people with disabilities were usually understood in the four countries in the study.

By *activity* we mean the more tangible elements and services of the projects. Since activities are of different kinds, we chose to distinguish between *measures* and *strategies*. Measures are the general activities the project offers, such as education, rehabilitation services, employment services, etc. Projects vary not only in terms of the type of activities performed but also in the number of activities offered. Strategies are features of the project that might be independent of the type of measure, such as community involvement, awareness raising, advocacy etc. These distinctions give us the opportunity to investigate possible relations between measures and strategies, as well as how the activity dimension relates to the two other dimensions.

Routinisation is a concept borrowed from the classical sociologist Max Weber and his analysis of how a charismatic religious movement develops into a community or a religious congregation. A charismatic movement, in its purest form (ideal-type) arises from prophecy. The prophet has his authority not from position or office, but by virtue

of his spiritual gifts (charisma). For the maintenance of this authority, however, it will require at some point some form of structure or organisation to secure a minimum of stability. It is this gradual establishment of a structure that Weber calls routinisation.

Weber also uses the concepts of charisma and routinisation to investigate more general patterns of organisational development. For our purpose, the concept is used to describe the process where an informally based group or association (typically of parents) gradually gains a certain level of stability through repeating certain procedures and securing certain functions and assigning certain duties to members with specific roles.

As a *dimension* (indicating that it might vary between projects) routinisation consists of three sub-dimensions; *formalisation*, referring to internal and external recognition; *standardisation*, which here refers to internal measures for predictability and stabilisation; and *professionalisation*. Each project has, as far as the data allows, been examined in relation to each dimension and sub-dimension.

One of our major points in describing the theoretical project in different dimensions is to avoid identifying, e.g. perspective as a special (initial) step of the project. In fact, we want to stress that the cases studied in the four countries can only be understood by treating the dimensions as parallel qualities characterising all phases of the project process. Specific cases are characterised by a certain profile in relation to the three dimensions. Some projects can, for instance, be described as "perspective heavy", others are heavier on activities, while others can be heavy on more than one dimension. These profiles can also vary over time. The important thing is that projects can not be understood in a logical process of intentions, means and results.

Chapter 4 - The perspective dimension

One of the key dimensions of the project process was based on the fact that someone in the local context strongly wanted changes in the everyday life conditions of people with disabilities. This was often parents striving for a better life for their children or employees in the disability services reacting against the marginalisation of people with disabilities. An in-depth analysis of what actually happened in the specific projects showed that this locally maintained wish for change could be understood within the theory of *social perspectives*, and more precisely in the framework of *social counter perspectives* maintained by parents, employees or other people with in-depth experience of what it meant to live with a disability. These local, counter perspectives constituted a very important, basic condition for the transcending projects.

The development of local (counter) perspectives
One point of departure for our understanding of the local perspective is provided by the Swedish anthropologist, Ulf Hannerz, who has studied what he calls the social organisation of meaning. As an anthropologist, Hannerz (1992) studied cultural phenomena, but he understood culture in the wider sense as social organisation of meaning, in both large and small scale social settings. To some extent our cross-national comparison also is a cross-cultural analysis. However, our understanding of the local projects essentially concerns local organisation of meanings as small groups of parents, professionals and other people in the community make sense of what it means to live with a disability from their specific positions and experiences.

Drawing on the theoretical work of the Chicago sociologists like Becker, Hughes, Strauss and Geer, Hannerz has developed a theory based on the concepts of *perspective, position, role, network, communication* and *the social distribution of meanings*.

People experience the world surrounding them from their own specific *position* in a society. Unemployed people and rural farmers tend to experience different things to university professors or middle class civil servants. In similar ways, people with disabilities have alternative and different experiences to non-disabled people. All human beings try to make sense of what we experience and remember the sense made of something when encountering the same phenomenon again. This accumulated stock of meanings constituted an important aspect of what Hannerz calls a *perspective*: "As perspectives are built up more or less cumulatively, they reflect previous involvements and experiences as well. The perspective is a biographical structure." The concept of perspective has been described in this way by Becker, Hughes, Strauss and Geer (1961).

> We use the term perspective to refer to a co-ordinated set of ideas and actions a person uses to deal with some problematic situation, to refer to a person's ordinary way of thinking and feeling about the acting in such a situation. [---] A person develops and maintains a perspective when he faces a situation calling for action which is not given by his own prior beliefs or by situational imperatives. In other words, perspectives arise when people face choice points. In many crucial situations, the individual's prior perspectives allow him no choice, dictating that he can in these circumstances do only one thing. In many other situations, the range of possible and feasible alternatives is so limited by the physical and social environment that the individual has no choice about the action he must perform. But where the individual is called on to act, and his choices are not constrained, he will begin to develop a perspective. If a particular kind of situation recurs frequently, the perspective will probably become an established part of a person's way of dealing with the world (Becker et al 1961, p. 34-35).

Here, we are most interested in what can be called *social* perspectives, i.e. modes of thought and action developed by more than one person facing the same problematic situation. The basis for social perspectives is communication, either face-to-face or mediated by a text or other kinds of media. When two, or more, people come to share a meaningful experience, something happens to their knowledge. My own efforts to make sense of something always appear with a certain transparency as my own point of view, while a shared meaningful experience becomes something we know. The more people are involved in the sharing, the more taken-for-granted the knowledge will be, and the more objectively it will be experienced.

An important contribution by Hannerz to the use of perspective, is based on his idea that meanings are socially distributed according to where people find themselves in the social structure of a specific society. The social positions and roles in a society are unevenly distributed and as a consequence we can also talk of a social distribution of perspectives and meaning in most societies. Before we move over to the specific sets of positions and perspectives developing in relation to disability, we shall look at another important characteristic of perspectives.

Becker et al. (1961) argued that it is not possible to make a sharp distinction between the ideas characterising a perspective and its actions. This is of special interest in our model of the theoretical project where local perspectives and activities constitute basic dimension. In fact, perspectives are potential actions. Sociologists and anthropologists have analysed this close relation between people's ways of understanding, and acting on, the surrounding world in different ways.

> Several of the anthropologists concerned with distributive models [of local meaning making] as mentioned before have had their own neologisms to denote the individual's portion of culture—"mazeway" (Wallace), "propriospect" (Goodenough), "idioverse" (Schwartz); Bourdieu's "habitus" is again in some way a similar notion. My own preference is "perspective", both because I see some value in using a more everyday term, and because it makes especially well the point (around which most sociology of knowledge, where it is often used, revolves) that things look different depending on where you see them from (Hannerz 1992, p.64-65).

Action space

If perspectives, at least to some extent, *are* projects, we need to ask why, after all, are there so few projects trying to improve living conditions for people with disabilities. Obviously, a great number of people with personal experience of disability, like parents of children with disabilities, have surely experienced problems that could have contributed to the development of important projects. Another way of phrasing our question is: *What has hindered positive change in the first place*?

One important answer is that all action requires space. In our studies of the archaeologies of the projects, we found that there had not always been sufficient space for the undertaking of the highly valued activities within the projects. In more theoretical language, one could say that the potential actions maintained within a specific perspective need space to be carried out. If there is not enough action space, the perspective will remain unrealised, building up a more or less silent wish for change. After some time there is an obvious risk that this wish turns into resignation. Most probably, this is what had happened to most counter perspectives concerning positive change for people with disabilities within the four countries studied. Thus, our first question could be given a more precise formulation: *What circumstances had opened new space for the transcending projects*?

The starting point of the transcending projects often was the transformation of personal dissatisfaction and a wish to turn something into a social counter perspective. This seems to be one necessary condition for the initiators to start doing something. Often, the social counter perspectives were maintained by the people involved in the project. On other occasions a key-person within the project shared his or her vision with a larger religious, political or other kind of community. On other occasions external donors could be the source of inspiration for a counter perspective. The necessary conditions for the perspective to be put into action were the sharing of a vision for change, empowering and mobilising local people. For the dissatisfaction and counter perspective to really translate into a project, there seemed to be the need for a leader, who could verbalise and translate the shared vision into concrete action, find recourses and establish good relations with the community. This person was often a parent with a respected position in the community, with financial resources and/or a formal professional background, often in an urban or semi urban setting.

A distinction can be made between *external and internal action space*. External action space here refers to the relation between a certain counter perspective (project) and all kinds of external conditions which could possibly influence the translation of the perspective's ideas into action. This is most often referred to in research as using the concept of action space. In our study, it seemed obvious that differences in democracy and citizen influence often defined an external action space in the specific countries. The important democratic changes in Romania and South Africa during the last 20 years have most probably influenced the action space allowing for the development of projects for people with intellectual disabilities. In all countries the national disability policies were becoming more responsive to the needs and rights of people with disabilities (at least on paper) and this also influenced the action space. However, democratic societies with a long tradition of supportive policies, like the Scandinavian welfare states also seem to have their external limitations to action space, this can be understood in terms of the inflexibility that often characterises highly bureaucratic and routinised service organisations.

Researchers using the actions space concept also talk about internal action space. The ways people think of their current living conditions and about opportunities for change constitute their inner action space. To a large extent, this is what we have called a perspective. Against the background of earlier analyses of human action and transcendence (von Wright 1970, Aronson & Berglind 1990, Kesthely 2006) it comes as no surprise that central concepts from action theory (like external and internal action space) can make productive contribution to our understanding of the characteristics of successful, developmental projects.

Making sense of disability positions, roles and experiences
The local perspectives in the case studies are, to a large extent, counter perspectives and are maintained as alternatives to a dominating perspective on disability in the four studied countries. All societies, modern as well as traditional, are organised according to the abilities and needs of non-disabled, so-called ordinary people with ordinary functioning abilities. An important aspect of these societal organisations concern people's making sense of everyday activities, demands, needs and production. Schools, houses and work are organised according to non-disabled people, often men. In many social settings disability is literally unthinkable in the practical sense of the word. This leaves little space for adults and children with disabilities who are often excluded physically, functionally and socially from ordinary activities, like schools, sports, leisure activities, marriage and work. Typically, most societies with well developed welfare states organise special schools and supported occupation for people with different kinds of disabilities. Such special services were seldom available in the four studied countries, with the exception of Romania where institutions played an important role. As a consequence, people with intellectual disabilities were often more or less excluded from areas of everyday life and deprived of much of what constitutes quality of life for everybody else.

A special representational expression of the dominance of non-disabled people in all the studied societies—and this is valid for most other societies—was often discussed in the national reports in terms of *stigma*. Erwin Goffman's (1963) concept of stigma is based on the idea that all societies tend to develop their own ideals and norms for what it means to be a normal man or woman. Stigma refers to a special social response to certain kinds of deviance, among others disability. The stigmatising way of relating to people who are regarded as deviant can be understood as a dominant social perspective on disability in the four studied countries, but also in most other

countries. People with a personal experience of disability, in most societies, find themselves exposed to a discrediting perspective, excluding them from many social settings and situations.

Most of us - and this is usually true in most societies - do not bother very much about the disadvantages and injustices linked to disabilities, until we get personal experience of what everyday life with a disability really means. Such experiences are precisely what parents of disabled children get and the lack of insight and understanding from other people is often experienced as if they lived in another world. Most parents experience a constant need for the services, treatments and other kinds of support that their children need. Some mothers and fathers with exceptional strengths and opportunities can find ways to receive a little more than other families. However, the ordinary societal organisation – based on the abilities and needs of non-disabled people – usually makes it impossible for most families to achieve what they need and want for their children. As a consequence, there is a hidden dissatisfaction and constant striving for improvement. This dissatisfaction and desire for change is often stronger in societies with less developed special facilities for children with disabilities. It is felt most keenly by parents who have the day-to-day responsibility for the child. This is why the mothers were so often very engaged, and played important roles, in many of the studied projects. This also explains the parental "force", their courage, risk-taking and persistence observed in the projects. What conditions are necessary to liberate this force and channel it into a developmental project? The most important answer found in the case studies was the development of a social counter perspective with enough external and internal action space!

Parental involvement in the transcending projects
It is not difficult to see that people with disabilities occupy special positions and roles in all the societies included in this study. To an important extent the experiences of such positions and roles are also shared by parents of children with disabilities. People in these positions and roles are confronted with similar problematic situations and as a consequence share similar experiences. This symmetry of experience and personal perspective constitutes the basis for the sharing that characterises social perspectives. However, symmetry of experience is not enough. Social perspectives also demand social interaction between people with similar experiences. Opportunities for people with disabilities to meet are often quite limited as was the case in many of the social contexts where local projects emerged. Parents, especially mothers, usually meet with other mothers to share experiences and sometimes to solve problems together. Consequently, mothers of children with disabilities seem to have played important roles in building and maintaining the project perspectives. On some occasions, the initiative was taken by one parent calling on others but on others it was a professional educator or therapist (see below) who provided opportunities for parents to meet and share experiences. In this way individual people's dissatisfactions became a collective desire for change. As a result, the parents also gained a new understanding and competence to engage in action for their children. It was not until this sharing of need and intentions took place that the parents' dissatisfaction and desire for improvement turned into a force in the true sense of the word. Another way of describing this is to say that contacts and sharing with others *empowered* the parents. In many of the projects, activities and interventions only engaged a few children and families at first but gradually the numbers increased. As the projects became more and more developed, involving more and more activities, they contributed to the development of the local

perspective. Thus, when parents, educators, and other professionals - and to some extent also children - had the opportunity to share experiences they could help develop the social perspective.

An important circumstance, known to contribute to the development of local perspectives, is that people interacting and sharing experiences also find themselves socially isolated from others. Hannerz quotes Hughes' analysis of the social organisation of locally maintained meanings in reference to subcultures as: "Wherever some group of people have a bit of common life with a modicum of isolation from other people, a common corner in society, common problems and perhaps a couple of common enemies, their culture grows"(Everett C. Hughes 1961, in Hannerz 1992, p.64). It is not difficult to see that the description of these everyday life conditions could apply to the mothers and the fathers of children with intellectual disabilities in the four countries. The descriptions of all projects include the isolation of the children with disabilities and their families. Even if enemies are not mentioned very often in the case studies, there are descriptions of several conflicts, for example, the conflict between the people engaged in the Kaimosi project and those who wanted a cattle-dip.

One of our main points here is that the contribution of parents, and parent's organisations in the transcending projects should not be understood as the introduction of something totally new, say the result of parental empowerment by a strong leader, professionals or change agents in a developmental project. On the contrary, most of the parental contributions should be understood as an expression of the special perspective already maintained by the parents. This perspective is rooted in their dissatisfaction with their lives and belief in better living conditions for their child and for themselves. To understand the favourable development of the project, it is necessary to be mindful of the conditions that first made it possible for the parents to realise the changes they had longed for. Here, the development of the social, parental perspective seems to have been important as well as the space of change created by the charismatic leaders.

The transcending power of parents sharing common experiences of dissatisfaction and despair is also reflected by Farbel and Markel (1994) reporting on experiences from Louisiana, USA. Compared to other states in the USA, Louisiana was late to introduce family support, respite care and subsidy programmes for families of children with disabilities. By the end of the 1990s, the state had the highest proportion of individuals living in large facilities for people with intellectual disabilities. As a consequence; "Families felt alone, frustrated, and powerless. They experienced extreme emotional and financial stress. Children often went without needed services because families wanted to keep them at home" (ibid: 373). In 1988, a state-wide conference on community integration held in 1988 provided the needed information and impetus for change. Speakers shared information about the principles and components of community and family supports. These ideas and programmes sounded like an unrealisable dream to people in Louisiana. However, an awakening began. The conference gave parents the opportunity to share their experiences and to develop their own vision of a service system that would meet their needs. When parents shared their experiences, Fabel and Markel describe; "the energy and enthusiasm in the room multiplied. A common vision had been developed, which each individual recognised as his or her own". A perspective was developed, that also led to (or contained) action, which gradually came to transform the system of services in Louisiana.

Against this background it is not surprising that parents played an important role in almost all the transcending projects. For a long time before the projects started, many of the parents had, most probably, experienced a deep dissatisfaction with their own and their children's everyday lives. To some extent they had also known what they wanted to change but not had the opportunity so far.

At least part of the new opportunities was created by the collective strength developed within the parental networks. Another important component has to do with one of the other characteristic themes identified in the national studies, namely the special type of leadership observed. We will come back to this later.

Staff counter perspectives
Educators and other kinds of employees in the disability services played as an important role in many projects as did parents. The case studies show that employees sometimes shared the counter perspectives of the parents. In some projects the central people were both employees and parents. Generally, the counter perspectives maintained by employees were not based on their professional positions and roles. On the contrary, it was often the current professional beliefs and routines that they reacted against. The staff worked with parents to change practices to provide better services. The employees too were driven by dissatisfaction with the current support and living conditions offered to children with intellectual disabilities. This dissatisfaction made them search for better practices and in this search they joined up with parents and other staff with similar experiences and aims. Thus, the local projects came to include both parents and staff working, at least to some extent, side by side. This is supported by Knoll and Racino (1994) who argued that the personnel who are employing best practices are discovering that in their daily work they are defining a new role: "Field professionals have found themselves, with all their professional credentials, needing to turn to people with disabilities, neighbours, and family members with no advanced degrees to learn the lessons essential to succeed within the new community context" (ibid:304).

To some extent, employees and parents became allied and shared the same counter perspective. However there were also differences. Special educators, breaking with old practices and introducing new programmes could be seen as professional innovators and if their new ways of working were recognised they could even be regarded as more professional than others in the same field. On the one hand, this could give them an advantage over the parents whose work only was considered as voluntary and seldom paid. On the other hand, being employed could also be a disadvantage on other occasions, for instance, when the head of the existing professional organisation, reduced the action space or simply replaced the professional innovator, as in the case of Arnsberg.

Community values and support
Two other characteristics, highlighted in the national reports, can contribute to our understanding of the local perspectives of the transcending projects. Both have to do with the fact that the social mobilisation of people maintaining a local (counter) perspective was supported by beliefs, values and traditions present in broader communities. These existed independently of the specific communities of parents, professionals and other supporters maintaining the local perspectives of the transcending projects. On some occasions, communities like for instance religious congregations, offered important inspiration and support to the local perspectives guiding the projects. On other occasions these supportive communities were political

movements (Happy Home), the local community where the project happened to be initiated (Vidyasagar) or a network of foreign donors and supporters (Pentu Voi).

Traditional beliefs and values, of for example, a religious congregation, are often more stable than the local perspectives and can therefore offer important support if they happen to be coherent with the basic ideas of such a perspective. Becker et al. 1961 make a distinction between values and local perspective, the latter being more related to a specific situation and the way people understand and act in this kind of situation.

> Perspectives differ from values in being situationally specific; they are patterns of thought and action which have grown up in response to a specific set of institutional pressures and serve as solutions to the problems those pressures create. Values, on the other hand, are ordinarily thought of as being generalised and abstract, capable of being applied to a great variety of situations. Perspectives are related directly to dilemmas faced by the people who hold them, while values do not need to have such direct connection. Perspectives contain definitions of the situation, as the actor sees it. While values are essentially statements of the worth or "goodness" of classes of things, perspectives contain such judgements, but also contain statements about the nature of the situation in which such judgements are to be applied. Finally, we include in perspectives actions as well as ideas; analyses of values ordinarily distinguish values from the actions presumed to flow from them (Becker et al. 1961, p. 37).

The second characteristic of the transcending projects, also relates to how these projects have been influenced by an existing value base and highlighted especially in the African national reports. This concerns the types of spirituality, everyday philosophies or interdependence like *Ubuntu* in South Africa and *Harambee* in Kenya. Basically, Ubuntu and Harambee can be understood as traditional ideas of interdependence and community within a family, a tribe or a village. The ideas seem to have somewhat different forms and histories in different regions and countries. Harambee being, for instance, associated with the work of the first Kenyan president and the independence movement, but they also seem to have similar roots in traditional African philosophy and cultures (Ramose 2002).

Community and interdependence are highlighted also in the national reports from India and Romania. In Hindu philosophy "doing one's karma" means giving support without expectation of any return and "shram daan" (literally meaning offering effort/labour) also refers to a kind of everyday interdependence, that to some extent seems to have influenced the development of the local project perspectives. The same seems to be true for Romania, where family or village interdependence today can be found in rural areas. According to the Romanian coordinator, the local perspectives maintained within projects like Lacrima special school and Pentru Voi centre are characterised by a philosophy of interdependence similar to the one described in South Africa and Kenya. However, it seems as if the Kenyan and South African projects probably have been more influenced and supported by a general spirituality or philosophy of interdependence present in everyday life of these societies than have the transcending projects in the two other countries studied.

From a European point of view, the lack of welfare state organisations and people's dependence on informal systems of mutual support might at first appear as

unfavourable conditions for projects aiming to improve living conditions for people with disabilities. However, locally based projects also seem to have some advantages compared to more bureaucratic, welfare state projects of the kind most European countries offer. These advantages have to do with the participatory character of local projects; local ownership and the fact that locally founded projects seem to be sustainable in a way of special importance in countries like India, Kenya and South Africa.

The South African report illustrates that Ubuntu could be challenged by more exclusive social community processes. Stigmatisation seemed, for example, to replace the traditional mutuality between members of a community, and even a family, in relation to a person with a disability. To some extent, the counter perspectives maintained by the parents and the staff engaged in the projects can be seen as efforts to include people with disabilities into the traditional spiritual philosophies of interdependence.

In conclusion, value systems and everyday philosophies of interdependence can create action space for innovative projects. Here, it is important to point out that inclusive value systems and philosophies of interdependence were not only counter forces against more traditional, exclusive belief and value systems but also against exclusive *societal mechanisms*. Communities are kept together by perspectives and values while societies are functional organisations relying on two major types of structures: the official, governmental organisation and the economical forces most often determined by a market. People with disabilities in the four studied societies – as well as in most other societies – are exposed to strong mechanisms of exclusion, for instance in the labour market. Like parental mobilisation groups in other countries, the people maintaining the local counter perspectives to a large extent also fought for space for inclusion against barriers raised by the principles of market-oriented competition and official societal structures developed by non-disabled people for non-disabled people.

Chapter 5 - Project activities

What defines the projects as a project is a set of coordinated activities. A perspective, as radical as it might be, does not alone form a project. It might provide the necessary energy and point out a direction to follow, and it might even contain action, but to become a project such actions must be coordinated so as to form a deliberate and purposeful set of activities.

When we talk about activity as a dimension in its own right, it is because activity, as an important part of a project, is separate from perspective, with its own set of characteristics. There is no causal link between perspectives and activities. One perspective can result in a number of different activities, in the same way as an activity can be justified and guided by different perspectives. That is not to say that perspectives have no influence on activities. Schools or rehabilitation centres might differ substantially in character depending on what perspectives guides their activity.

This is why we distinguish between two different meanings or aspects of activity. As indicated above, we will refer to the two as *measures* and *strategies*. By measure we mean the type of activity or service offered, such as education, employment, living arrangements, rehabilitation etc. Strategy, on the other hand, refers to the more

specific design of the measure or the types of interventions characterising the measures offered, such as advocacy, awareness raising, independent living, various inclusive interventions etc.

Measures
Considering the measures offered by the projects selected for this study, they vary both in terms of number and in terms of type. As revealed in table 1, five of the projects offer educational services only. A closer look at the projects would reveal that this is a question of definition. Most schools offer additional services, like Lacrima School in Romania which even offers respite care by organising leisure activities for the students until six o'clock in the afternoon. Other schools offer speech therapy, car mechanics etc, but the projects are basically schools. It is the way of running the school that stands out. Some projects offer two measures while four projects offer three or more. Projects like Pentru Voi in Romania and Vidyasagar in India offer today a large range of different measures and services.

Based on the national reports we see that all projects started with only one measure, most often a school or a vocational centre, and some of the projects have then extended their range of measures as time has gone by. It is apparent that projects started by parents of small children started as schools while projects started by parents of adolescents, started as day centres or vocational centre. It is also evident that projects started by parents and where parents have continued to play an important role in running the project, have extended their scope of activities, reflecting the changing needs and new aspirations of the participants. For projects started by professionals, on the other hand, or projects where professionals took over the responsibility early, the scope of measures seems to have remained the same. An exception to this is GIMRC in India, started by a medical doctor, which has a variety of activities. The most likely explanation is that GIMRC was restarted, rather than totally new. It was a project that was about to die, and which had a variety of activities even before it was restarted.

It can be concluded that it is not the type of measures per see that determines if the project is successful in making a difference in the lives of people with disabilities. It is rather the ability to be sensitive and to constantly develop and adapt to the locally experienced needs and aspirations of the participants and to use opportunities in the local context.

Strategies
Considering the strategies used in performing the project measures, the variety is perhaps fewer than expected. One of the things that struck us was the similarities found in the strategies used by projects, irrespective of the type of measure offered. It was these strategies, not the choice of measures that distinguished these projects and made them stand out. One way to understand this is that the choice of measure is determined by the needs of the people targeted by the project, while strategies more directly reflect the local perspective and give the project its energy and direction. If the population targeted is children in school age, the measure chosen will most likely be a school, but not just any school. There are many special schools in Romania, but Lacrima School accepts the children that are denied access to the other special schools. In the same way there are many agencies offering vocational training and sheltered work for people with intellectual disabilities, but Vidyasagar in India, Pentru Voi in Romania and Astra in South Africa are consciously working to improve the working abilities, self esteem and opportunities to reach personal goals

for the service users. Even Mathare School, operating from a very deprived area of Nairobi in Kenya, is trying to achieve this for some of their graduates, through cooperation with enterprises and NGOs in the community.

Being visible in and actively involving the community is one of the most common strategies used across projects, which clearly reflects the counter perspective characterising these projects. The stigma attached to intellectual disability makes many communities hesitant and sometimes even hostile to the ides of having organised activities for intellectually disabled in the community. By actively exposing people with intellectual disability in the community, by opening the school or the centre to the public, using the public room and public services, together with active awareness raising, has made many of the projects able to substantially change the public attitudes towards people with intellectual disabilities and made the projects and the people served included members of the community. Many projects have also created opportunities for people with intellectual disability to represent themselves in conferences or meetings, in their own county and abroad, hence contributing to self esteem and self advocacy and strengthening their possibilities to talk for themselves and influence their own life.

The strategies mentioned in figure 1, which are strategies found in all countries, such as community participation and involvement, advocacy, awareness raising, exposure, capacity building, emancipation and self representation are all strategies with a similar direction; the moving away from excluded, hidden or subordinate positions, towards self determination and inclusion. And the interesting thing is this direction is not directed by donors or international organisations. Such organisations might very well have provided important facilitation and support, but the direction of these projects is first and foremost anchored in local perspectives and experiences.

Chapter 6 – Routinisation

Leadership
Leadership was highlighted in all the four national reports as a favourable condition for the transcending projects. All the reports also underline the importance of the special character of the leader for the projects. In our analysis of these characteristics, we have found it productive to relate them to the theoretical leadership concepts already introduced. Weber (1946) makes a distinction between three different types of leadership: rational, traditional and charismatic leaderships. The first is based on legality and is often the model for political, administrative and industrial leaderships in modern societies. The second is based on the belief in tradition as sacred and the primordial legitimacy for the leader. In modern societies churches present the best examples of this type of leadership but examples of earlier feudal structures of patrimonial leaderships are also discussed by Weber. The charismatic leadership is often illustrated by the extraordinary characteristics of the leader as a person and the new normative order maintained by the leader and his/her supporters.

The charismatic leader
It is interesting that, even though the majority of cases included in this study are well established service organisations, with professional staff and firm governing bodies, some even being part of government structures, they all seem to have started as a

revival, or at least to some extent in opposition to an established order. The exception is perhaps Arnsberg centre in Romania, which was actually set up by public authorities, after the initiative of and support from the city of Arnsberg, Germany. But even here the project radically exceeded existing practices in the field. All projects represented what we have called a counter-perspective, a breakthrough, anchored in some sort of experience, revelation or acknowledgment strong enough to act upon. In most cases it also seems that there were individuals acting as agents of these breakthroughs, who by virtue of their personal abilities and charisma came to take a leading role in the revival. They acted, in Weberian terms, as *prophets*, or as *charismatic leaders*. Since the presence of charismatic leaders seems to be a characteristic feature of the projects under study, Weber's concepts of charisma and the routinisation of charisma seem valuable as a conceptual framework for our understanding of the development of these projects, and especially of the gradual organisation that they go through.

A prophet, being an *ideal type* in Weber's methodological framework, should be understood to mean "a purely individual bearer of charisma" (Weber 1964), a person that other people are willing to follow. The role of the religious prophet was for Weber the prototype, or the purest (though, not the only) form of charismatic leadership. In his foreword to the English translation of Weber's *Sociology of Religion*, Parsons (1964) says that "the prophet is above all the agent of the process of breakthrough" (Parsons 1964: xxxiii). Parsons notifies two points about Weber's concept of charisma that is of particular importance to such breakthrough: "The first is the focus on the individual person who takes the responsibility for announcing a break in the established normative order and declaring this break to be morally legitimate, thereby setting himself in significant respects in explicit opposition to the established order" (ibid: xxxiii-xxxiv). The second, he says, is Weber's insistence that there even is "a crucial non-cognitive aspect of it, namely that of *commitment* to the break and the order embodied in the break" (ibid: xxxiv), hence representing an ethical imperative for action.

It is notable that even though charisma is most often described in individualistic terms, Weber did not only treat charisma as a property of individuals but also of a normative order. It might perhaps be possible to see parental power, particularly voiced by some charismatic parental leaders, juxtaposed in such a way as to form a normative order embedded by charismatic authority. The charismatic authority hold by some of the parental leaders owes much to their status as parents.

The relation between parents and professionals has an interesting parallel to Weber's distinction between the prophet and the priest. As Weber notes: "The personal call is the decisive element distinguishing the prophet from the priest. The latter lays claim to authority by virtue of his service in a sacred tradition, while the prophet's claim is based on personal revelation and charisma. It is no accident that almost no prophets have emerged from the priestly class," (Weber 1964: 46). For the same reason, it is probably not accidental that most of the projects chosen for this study have been initiated by parents.

And, according to Weber: "The source of devotion is here the ever new, that what goes beyond everyday life, the unexampled and the emotionally entranced that it implies" (Weber 1971: 98). When the ethical imperatives implied in the revelation becomes routine, the devotion decline correspondingly. Weber refers to: "The carefully cultivated postulate that the apostle, prophet, or teacher of ancient

Christianity must not professionalise his religious proclamations", (Weber 1964:48). He ascertains that: "It is characteristic of the prophets that they do not receive their mission from any human agency, but seize it, as it were" (Weber 1964: 51). Professionals, like the priests, by contrast, hold their power by virtue of their office: "Even in cases in which personal charisma may be involved, it is the hierarchical office that confers legitimate authority upon the priest as a member of a corporate enterprise of salvation" (Weber 1964: 47). The best example here being the former director of Arnsberg centre, who obviously had a personal charisma, by which he also managed to bring about a certain breakthrough, but who was bound by his loyalty to the public authorities who decided to replace him when he exceeded this loyalty. It is notable that the other professionals did not (openly) oppose this replacement.

But even though charismatic authority is crucial to sustain the devotion of the followers, charismatic movements are difficult to maintain over time. At a certain point it becomes necessary to establish some basic structures and to formalise certain roles, not least for economic purposes, to secure sustainability. Weber describes this process in relation to the forming of congregations. He states that a congregation or a religious community: "…arises in connection with a prophetic movement as a result of routinisation (Veralltaglichung), i.e., as a result of the process whereby either the prophet himself or his disciples secure the permanence of his preaching and the congregation's distribution of grace, hence insuring the economic existence of the enterprise and those who man it," (Weber 1964: 60-61). He even argues that what we mean by "organisation" is precisely this securing of enterprise to sustain authority (Weber 1971: 101).

Hence, organisation is a way of securing an enterprise, a way to sustain a certain set of activities, by making them rely on routine and on a set of formal contracts, instead of the devotion to a charismatic authority or a normative order. The link back to the counter perspective from which the breakthrough arose in the first place becomes weaker as the activity is no longer dependent on devotion or the charismatic preaching on which it rested. Preaching, according to Weber, which is normally something uniquely associated with prophecy and prophetic religion, represents a collective instruction concerning religious and ethical matters, or an imitation of such. But as a rule, he says; "preaching declines in importance whenever a revealed religion has been transformed into a priestly enterprise by routinisation" (Weber 1964: 74-75).

Formalisation, standardisation and professionalisation
Leaving Weber here, we believe that routinisation, as a dimension, is not the organisation as such, but rather some aspects of organisation, i.e. the processes through which perspective are gradually revealed or replaced by routine as the basis of sustainability. In relation to the projects selected for this study we believe that three such aspects or processes are particularly important: One is *formalisation*, referring to the recognition and acceptance gained both from members and from a wider public, for being an organisation. The group of people initiating the project are no longer seen merely as a group of people, but as a formal entity. Formalisation is both an internal and an external process. It includes the establishment of governance and legal structures, as well as the (formal or informal) assignment given by the social environment to perform a certain role. This represents a gradual integration of the project into a formal structure, by which the project is given public tasks and obligations, as well as the recognition and economic resources that comes with it.

The most typical examples from this study are projects like Mathare special school in Kenya and Lacrima special school in Romania, both accredited formal public schools. The same is partly true for all the special schools in the study, also the private schools too, as they need public recognition and approval to perform as schools. For private schools it means that they must comply with public regulations and curriculum, while for other, like Lacrima and Mathare it also means that the public authority command the recruitment of teachers, leaving little space left for radical perspectives.

The second aspect of routinisation, and probably its strongest agent, is *standardisation*, referring directly to the process of making routine. To be *recognised* as an organisation is not only a question of formalisation, but also about identifying a set of tasks, actions and procedures. Fulfilling obligations or meeting expectations from the environment requires a certain predictability which is easiest obtained, over time, through the standardisation of roles and procedures. The standardisation of roles and duties also implies a clear distinction between those who are organisational actors and those who are not; those with a legitimate role based on office and position rather than on devotion. A good example of this is discussed in the Romanian national report, in relation to Lacrima School in Bistrita and Pentru Voi centre in Timisoara. Despite the fact that the directors of these projects were both parents, they found that parental participation had decreased substantially since the early stage. Both directors admitted this with a certain disappointment. From being a revival, based on a clear counter perspective, and a common vision among parents of creating together a better life for their children, the projects gradually institutionalised into becoming an independent service facility, with a clear organisation and its own monitoring structure. As indicated in the Romanian report, this probably reflects a more general tension between voluntarism and organisation. The more organised the less space it gives for voluntarism and, we could add, for parental devotion. Even with strong sympathy for the organisation, the natural sense of belonging, of being part of a revelation, decline proportionally to the institutionalisation of roles and organisational structures.

The third agent of routinisation seen in these projects is *professionalisation*. Even though most of the projects were started by parents, most of them, due to the activities offered and the gradual organisation and formalisation they have gone through, have developed a certain degree of professionalisation. The degree of professionalisation varies, from the CBR project Mother Theresa and Happy Home in South Africa with fairly low levels of formal professionalisation, to the special schools that require formally trained teachers. It appears the professionalisation, (in the same way as formalisation and standardisation) in most projects happens at the expense of parental involvement, also, to some extent, at the expense of perspective; even though perspectives are also adopted by and sometimes even introduced by professionals. As we have seen some projects, such as Wizz Kidz and Astra in South Africa, and GIMRC in India were started by professionals, even those partly driven by counter perspectives. It might be, however, that these projects, together with Arnsberg centre in Romania, which was started by public authorities as a professional rehabilitation centre, have a slightly stronger character of routinisation and is weaker on perspective.

Chapter 7 - Projects in profile; the theory applied

The arguments developed in the previous chapters indicate a negative relation between perspective and routinisation. First of all, all organisations face the risk of routinisation. In fact, organisation is in itself a kind of routinisation, in that it implies a certain degree of formalisation of roles and obligations. However, if routinisation exceeds beyond what is necessary to sustain organisational procedures, it risks draining out the energy and vitality provided by local perspectives. Routinisation most often happens on the expense of local perspectives. The relation probably also implies that a strong local perspective can prevent the routinisation to dominate. We have seen, however, that strong local perspectives often imply a gradual extension of the scope of activity. This will require a more extensive organisation which might again increase the risk of routinisation.

In examining the relations suggested above, an attempt was made to classify the projects according to the three dimensions. This required, first of all, a collective discussion about how to score the different dimensions. We started by trying to characterise one project by grading its position on each of the dimensions, using a scale from 1 to 5. Not surprisingly, *perspective* was the most difficult dimension to score. It became clear that perspective could mean slightly different things, and that the initial (counter) perspective had for some projects transformed into more theoretical or advanced ideological perspectives. We also saw that some projects had developed various forms of professional perspectives. We decided to define perspective as close as possible to the use of Hannerz (see chapter 4), meaning the "coordinated set of ideas and actions" derived from the local experiences and dissatisfaction which motivated the initiation of the project in the first place, some times developed into a more firm ideology. It means that it does not include specific professional perspectives or ideologies. *Activity* represents the scope of the project, both in terms of the number of measures offered and in terms of people served. *Routinisation* represents a weighed combination of standardisation, formalisation and professionalisation. The actual scoring was done, to the best of our judgment by comparing projects to each other. The scoring was done in a common meeting, in which the local coordinators characterised and graded the projects from their own country, scrutinised by the rest of the team.

Concerning perspective, four projects, one in each country were graded 5, indicating that these projects were particularly heavy on perspective. These were Vidyasagar in India, Happy Home in South Africa, Mother Theresa in Kenya and Pentru Voi in Romania. Only one project, GIMRC in India, was given grade 1, and two projects, Mathare in Kenya and Arnsberg in Romania were given grade 2. The rest (six projects) got grade 3, as they appeared at the time of the study.

Considering activity, four projects were given the grade 5 and four more got the grade 4. Only one project (Mother Theresa) got grade 1 and none got grade 2. We see that even though all projects started quite modestly, usually with one activity for a limited number of people, most projects had by the time of the study developed a wide range of activities. This was true also for the projects with only one major activity or measure, such as Wizz Kidz and St Catherine, both schools. Mother Theresa is the newest project and has not yet had the time to develop a wide range of activities.

The different aspects of routinisation are of course difficult to weigh together. Still, it did not seem difficult to score the different projects. We see that three projects are regarded as highly routinised, having received the grade 5. These are GIMRC in India and Wizz Kidz and Astra in South Africa. On the other end of the scale, Mother Theresa is given grade 1 and Happy Home 2. Three projects are given the grade 3 and the rest (four) a 4.

A certain degree of routinisation is inevitable, especially for projects that have been in operation for some time and for projects that serve many people or have developed a wide range of activities. For a service organisation (which most of these projects are), a certain standardisation, formalisation and professionalisation, is required by law and to secure sustainability and accountability. Still, the degree of routinisation varied between the projects. The question we raise is whether the degree of routinisation varies in relation to the extent to which projects have been able to maintain a social perspective, and to the scope of activities developed.

It is perhaps not all that easy to distinguish a clear pattern from the table below, but for us, familiar patterns seem to emerge. It would probably have been even clearer if the scale had been more detailed. GIMRC in India and Arnsberg in Romania are the two projects in which a local (counter) perspective is least visible, and was not very evident in the beginning; although, the professionals who were responsible for the initiation were very enthusiastic and quite radical in their orientation, especially at Arnsberg. Parents did not play any significant role in the initiation of these projects. Even though they have had a significant impact on the quality of life of many people with intellectual disability and developed much of the same strategies characterising the rest of the projects, they are the most routinised of the projects selected. Both are run by the public sector, have a very firm and formal organisation and they are both run and managed in compliance with professional values.

Mother Theresa, on the other hand, is a project started and solely run by parents. It reflects a strong local counter perspective and has (so far) hardly developed any formal structures. This is probably because this is the youngest of the selected projects. It supports the assumption that routinisation is a process that develops over time, quite often at the expense of the vitalisation provided by local perspectives.

It is perhaps more interesting to look at older projects which have maintained a strong local perspective. Happy Home, Pentru Voi and Vidiasagar, all graded 5 on perspective, are eight, 10 and 21 years old respectively. What they have in common is also an extensive range of activities (all graded 5), gradually developed as the needs and aspiration of the participants changed. Still, they have all managed to resist a strong degree of routinisation (2 for Vidiasagar and 3 for Pentru Voi). We see that Astra in South Africa, also graded 5 on activity, does not reflect the same degree of local perspective (3) and is far more routinised (5). The same is true for Kaimosi, Mathare, and Wizz Kidz, all graded high on routinisation despite a more modest scope of activity.

Table 3: Classification of projects in relation to the three dimensions

Projects	Perspective	Activity	Routinisation
GIMRC	1	4	5
Vidiasagar	5	5	2
Mentaid	3	4	3
Mathare	2	3	4
Kaimosi	3	3	4
Mother Theresa	5	1	1
St Catherine	3	4	4
Happy Home	5	5	2
Whizz Kidz	3	4	5
Astra	3	5	5
Lacrima	3	3	3
Pentru Voi	5	5	3
Arnsberg	2	3	5

In conclusion it seems as if projects that are heavily routinised lose energy and perspective. Projects that are seen as the most outstanding are those that have managed to keep the perspective, develop a range of activities responding to the local needs and opportunities, while defending the organisation from being heavily routinised. This often means avoiding complete take over by government. Whereas government responsibility is welcomed and necessary, it is also a challenge to find partnerships that leave influence to perspective holders and flexibility to adapt and develop activities. Pentru Voi is an organisation that has managed to formalise such partnerships in an exiting and innovative way.

Chapter 8 - Patterns, conclusions and implications

Introduction
The cross national comparative analysis presented in this report is based on in depth qualitative case studies of 13 individual projects in four countries; India, Romania, Kenya and South Africa. The case studies were conducted by researchers from the four counties participating in the study, each of them studying the projects in their respective countries. Both the criteria for selecting projects to study, the selection process itself and the actual field work were carried out by local researchers, assisted by a national team with representatives from local academic institutions as well as disability organisations and NGOs. Scientific and technical advisors from Scandinavia played a role in planning, coordinating and advising throughout the research process but substantial efforts have been made to secure the cultural validity of the study.

The original idea was to do an evaluation of a number of projects meeting a certain set of prescribed quality of life criteria, with the purpose of developing a model of good practice for projects aiming at improving quality of life and promoting inclusion for people with intellectual disabilities. This idea very soon ran into problems, making the development and design of the study into a useful learning experience.

We learned first of all that criteria for selecting successful and innovative projects must be culturally valid. What counts as valid indicators of different quality of life dimensions vary substantially between countries and contexts. Secondly, and consequently, we learned that the idea of developing a model of best practice to be applied across cultural contexts would never work. We understood that searching for a common strategy to promote innovation and success in development work was a dead end. We realised that since the cultural contexts of the four countries were so different, the only way to discover possible commonalities was to search for the culturally specific. Hence, we finally decided to identify and select projects that were locally regarded as successful in improving quality of life for people with intellectual disabilities, based on culturally validated criteria, and to let local researchers study these projects in their own right. A common methodology framework was developed to secure the same type of data, i.e. to secure the richness of description and to secure that all relevant voices were heard, making it possible to grasp the essential factors and processes in each project.

Looking back, it is obvious that the methodological development was an important lesson learnt in the study as a whole. As mentioned, the methodology finally adopted can be characterised as *collaborative* with the aim of developing a comparative approach, valid and sensitive enough to fit the specific national projects contexts and, at the same time, guided by a common frame of reference allowing for cross-national comparisons. The essence of the collaborative approach was to engage the coordinators from all the different national and cultural contexts in the process of gradual decision-making. The scientific advisers first proposed some common guidelines and criteria. These were validated in each country by the national coordinators and completed by guidelines and criteria of special importance to a specific nation, region or local context. These jointly constructed guidelines and criteria were then applied in all the four countries to identify outstanding projects, which were explored and analysed against the background of its specific context. Each case study was presented in individual reports and in each country a comparative analysis was done on basis of all the national projects. As a result of these comparisons, the national reports present a set of key factors that attempt to explain what made the selected projects so outstanding in their historical, cultural, economical and political context. These case studies and national reports have formed the basis for the cross national comparison presented in this report.

The analysis in summary
To be able to compare patterns and findings across cultural contexts a new conceptual framework was developed. The concepts introduced were what Strauss (1987) has called a sociologically constructed concept, in the sense that they were taken from the social science literature, linking the analysis with a wider theoretical context. But the choice of concept and the analytical framework used are grounded in the case studies and comparisons made in each country, which represent the data for the cross national analysis. It was through the process of working with these data that the theoretical framework was developed, making the framework itself a product of the analysis.

Three dimensions represent the main pillars of this conceptual framework. These are *local (counter) perspective*, *activity* and *routinisation*. By systematically relating the patterns and findings from case studies and national reports to this theoretical framework and to the meaning contained in each concept a new pattern emerged, forming a story about how these projects grew and developed. It is this story we will

now tell in brief. It is important to emphasise that this is not the story of each and every one of these projects. It is a story containing what we believe to be the most important elements about these projects providing a deeper understanding of what makes some projects successful. It is a story in which all the projects fit, although some projects fit better than others.

Almost all projects started as a response to a local dissatisfaction with the prevailing opportunities for people with intellectual disabilities. This is also why most of the projects were initiated by parents of disabled children. They are normally the most affected by such lack of opportunities as long as the children are small. A phrase used by parents in many of the projects is: "We wanted something better for our children".

But this dissatisfaction was normally not enough. Three factors seem to have been particularly important for this dissatisfaction to transform into a project. One is that people with the same dissatisfaction – quite often it was more a question of anger and despair – met and shared their experiences. It is through this sharing of common experiences that a local perspective – or counter perspective – is formed, quite often in contrast to the prevailing hegemonic perspectives in the community or country. This is most often the first step to an association of parents. We also see a few examples of professionals, including a priest, who showed the ability to identify with the needs and interests of people with intellectual disabilities. They then become strong perspective holders and allies of the parents.

The second factor is the presence of a person who is able to articulate and represent this local perspective, a charismatic leader ("prophet") who has the sufficient respect, power and resources to unite a group and to coordinate their action. A local perspective and a "prophet" to voice it give the projects their energy and direction.

The third factor relates to the issue of action space. We have made a distinction between internal and external action space. Internal action space has to do with the personal beliefs about what is possible to accomplish. Isolated parents most often feel powerless. When they meet other parents, with the same experiences they are empowered, i.e. their internal action space increases. External action space has to do with the options given for action in the actual community and society. We have seen that dominant or hegemonic perspectives in the community and society, and particularly the stigma attached to disability represent obstacles to action. But external action space is also limited by bureaucratic regulation, lack of resources and lack of leadership. We have seen how the presence of charismatic leaders who are able to voice the local perspective and to coordinate action has extended the external action space. So has also the financial and moral support from communities, NGOs and external facilitators.

Hence, the most essential characteristics of successful projects as observed in this study is the presence of a local (counter) perspective, anchored in shared experiences of dissatisfaction, providing energy and direction for local action, and a leadership with the sufficient respect and power to voice this perspective, to bring about a certain inner action space and to coordinate local action. A successful project also needs an external space for such action, which, in addition to good leadership, often requires a certain acceptance and support from communities and external partners.

The concrete measures offered or performed by projects vary according to local needs. If the initiators were parents of children with intellectual disabilities the initial measure was typically a school. If the engagement of parents continued as the children grew older, the projects most often extended offering other measures such as vocational opportunities or supported living arrangements. In cases where parents were not that central or where parent's engagement declined over time, the initial measure remained the central or the only focus of the project. What distinguished these successful projects from other schools or vocational centres was not the choice of measure but how the measures were performed. This more directly reflected the local (counter) perspectives which justified and fuelled the project from the start. All the projects, irrespective of the type of measures offered, shared a set of strategies giving the project a certain profile and direction. Through community involvement, awareness raising, advocacy, capacity building, self representation and extensive use of the public room, all projects were directed towards more or less the same goal; to promote the acceptance, participation and inclusion of people with intellectual disabilities in the local community and the society at large.

Looking at the projects from a biographical perspective not all of the projects managed to maintain the vitality and energy characterising the early stages. One reason for this is the gradual routinisation that takes place in all projects. Some form of routinisation is necessary to secure a certain stability and sustainability. These could be an organisational structure, with a certain degree of formalisation, a certain standardisation of procedures to secure predictability or the professionalisation required to offer certain services and measures such as education and rehabilitation. In fact, formal organisation and routinisation often are the only ways of creating the credibility necessary to get a large enough external action space for the survival of a local project. But through such routinisation there is also a risk of draining out the vitality and energy provided by the local perspective. It might also be a risk that the satisfaction provided by the projects risk loosing the ties to the dissatisfaction and despair in which the local (counter) perspectives were grounded. Thus, a certain routinisation is necessary and even desirable to succeed. However, it must always be balanced in relation to the flexibility and energy necessary to sustain its vitality and its ability to progress in relation to changing needs and opportunities.

Other similar findings
As is sometimes the case in studies like ours, the final results of the comparative study turned out to be confirmed by a lot of earlier findings, which gradually were brought to our attention as the configuration of the comparative results emerged. In fact, some of the key findings of the cross-national study can be related to what has been called a paradigm shift in the knowledge field of development projects. Here, we have chosen to present a summary of this paradigm shift, as described by, Allan Kaplan (1999)[9], one of the directors a *The Centre for Developmental Practice*, a non-governmental organisation in South Africa created during the growth of the democratic regime and the fall of apartheid. His summary has a special interest as a confirmation of what characterises development projects and it reflects an experience of working with more than 500 development organisations first of all in Africa but also in Eastern Europe. From his practical experience, as well as his knowledge of the more theoretical developments in the studies of development projects Kaplan compares traditional development projects to what he calls the new paradigm of developmental work.

---

[9] The paper has been published as a booklet by SMR, Svenska Missionsrådet

Figure 2: Kaplan's model of the paradigm shift in developmental work

Traditional development work	New paradigm development work
D starts when an intervention is started and implemented	D has always begun before interventions are started
D is created and engineered	D can only be facilitated
D is linear and predictable	D is creative and unpredictable
D presumes there is something wrong that should be corrected	D is an expression of diversity and local perspectives and solutions
D must have clear ends against which results can be evaluated	D has few predetermined ends but opens up for local initiatives and creativity

Of special interest to our study is the discussion on evaluation and research. According to Kaplan, the usual focus of the old paradigm is to evaluate projects in terms of replicability and sustainability as well as assessable and quantifiable qualities like financial strength, skills, organisational structure and procedures. In the new paradigm this is replaced by a focus on the change process itself, the unique character of every project and its "response-ability". Thus, evaluations and other types of project studies must take into account the project's and key change agents' ability to keep moving, changing and improving their "response-ability" to inevitably shifting circumstances, rather than assuming that those circumstances will ever be finally and successfully resolved, once and for all: "The evaluation of development interventions must therefore take place against the background of the specific development processes which has been intervened into, not against the stipulated ends in a project document. This too has radical and far-reaching implications. There is often far more than might have been gained beyond the boundaries of original expectations, if we are only open to looking beyond these boundaries, and beyond the boundaries of our own input" (Kaplan 1999, p 13).

Here, we also want to refer to a classical study in the field of development projects, Albert O. Hirschman's (1967) study of 11 development projects funded by the World Bank. One of Hirschman's most interesting findings was that successful projects very often were characterised by a certain lack of initial awareness of difficulties ahead. If the initiators had been aware of these challenges they would most certainly not have engaged in the project. All the same, the projects proved to be successful as a result of the creativity stimulated by the unexpected challenges. The key-finding here is that creativity can not be planned beforehand and really innovative projects demand large, uncontrolled, action space.

Hirschman explains the power of the principle of the "hiding hand" by looking at the basic conditions guiding development projects:

> [I]t is quite plausible and almost trite to state that each project comes into the world accompanied by a set of partially or wholly offsetting potential developments: (1) a set of possible and unsuspected threats to its profitability and existence, and (2) a set of unsuspected remedial actions that can be taken should a threat become real (Hirschman 1967, p. 11).

Further on, Hirschman outlines the precise meaning of his principle:

We may be dealing here with a general principle of action: Creativity always comes as a surprise to us; therefore we can never count on it and we dare not believe in it until it has happened [---] Or, put differently: since we necessarily underestimate our creativity, it is desirable that we underestimate to a roughly similar extent the difficulties of the task we face so as to be tricked by these two offsetting underestimates into undertaking tasks that we can, but otherwise would not dare, tackle. The principle is important enough to deserve a name: since we are apparently on the trail here of some sort of invisible or hidden hand that beneficially hides difficulties from us, I propose *the principle of the Hiding Hand* (Ibid, p. 13).

An illustration of this principle in our study was the local perspectives (the basis for the start of the projects) seldom included plans for all the activities later undertaken during the life of the projects. On the contrary, the most innovative projects transcended the initial goals as activities were developed and new demands and opportunities were discovered. In this way the perspectives were continuously enhanced. Interestingly, projects where this continuous elaboration stopped, often lost their innovativeness and turned into ordinary schools or services.

Implications
The most obvious implication, as stated earlier in the chapter, is that there can not be such a thing as a model of good practice that can be imposed upon local projects. A successful project can not be designed in advance; it must grow from below and develop its own preconditions. It is the local dissatisfaction, anger and despair, shared with others with the same experiences and voiced by people with legitimacy and trust that has the power and direction to transform into successful projects. That does not mean that such processes cannot be facilitated. The worst enemy to such progressions is isolated parents. Having seen the power of shared experiences, we believe that providing arenas were parents can meet other parents can be an effective strategy. Supporting local "charismatic leaders" and the perspectives and arenas where these seem to emerge is another possible strategy. It is important to trust the energy and direction entailed in early phases of such actions even though they might not apply fully to the political correctness desired by external organisations and possible donors. It could also be a good strategy to facilitate meetings and experience exchanges between local "charismatic leaders" working in similar conditions but definitely not replacing them with other leaders or more "correct" perspectives.

Based on discussions in the reference group and consultations with the national coordinators we have tried to look at a few possible implications of the cross national study for how the transcending projects can be identified, supported so projects can keep their energy and perspective, despite routinisation.

Our analysis shows that even the most marginalised and excluded people in a society can be mobilised and empowered to take active part in social change processes. This has often been seen as too difficult by many development practitioners. It would be interesting to study more in detail how to reach these groups and how to facilitate their local perspectives to develop and transform into projects. There could be a number of ways, for example:

- The internal action space (belief that change is possible) could be facilitated through visits of role models who used to be in the same marginalised and

difficult situation but have managed to improve lives. Visibility of people with disabilities and their families also contributes to general awareness raising.

- The external action space could be facilitated by creating and supporting arenas for people (people with disabilities, parents and employees in the disability services etc.) to meet and share experiences, and thus facilitating the development of social counter perspectives.
- It would probably be a good idea to identify and support emerging 'charismatic leaders' articulating such counter perspectives, so that they could realise their vision more easily. The ability of the leadership to carry and share a vision and to be able to translate this vision into action is of great importance and groups need to carefully consider this, as do external supporters.

Furthermore, agencies that support projects and organisations could improve their practices, taking the following into consideration:

- Applications for funding of projects should not demand too much in terms of precise goals, validated methods and predictable results. Many of the transcending projects risk rejection. According to our findings, projects that stand out have started as informal groups in local communities with a strong vision and a willingness to take huge risks. Their success often lies in their flexibility and ability to adapt to changing needs and opportunities in the local context.
- Too much focus on or demand for formal structures, planning systems and professionalism (routinisation) could lead to stagnation of dynamic change processes. There is a need to find ways to safeguard the local perspectives in projects and to find private-public partnerships that allows influence and involvement by the perspective holders to continue.
- Our study indicates that the tools currently used for project evaluations and assessment of "organisational capacity" might need reviewing. Some of the qualities that are found as essential in this study are not part of tools presently used by agencies.[10]
- The cross-national study also indicates that it might not be a good idea to promote models of good practice that can be implemented elsewhere. On the contrary, our experience is that transcending projects often are based on local perspectives and external support therefore should be directed to projects that are working in close interaction with the local communities and are sensitive to local needs and opportunities. The only way of using good examples is to make it possible for leaders of local projects to demonstrate their projects to others in similar situations.

A key area of concern is how to steer the processes of routinisation in favourable directions, to avoid the loss of energy and direction. As we have pointed out earlier, routinisation, e.g. in the form of good management, is necessary for a project to gain strength and to become sustainable. Thus it is not a question of avoiding routinisation but precisely to give it a favourable direction. How to do this is an area which needs further research, but we believe that some of the measures could be:

- defending the local influence within the project by e.g. formalising roles and duties for volunteers, minimising government and donor bureaucracy and regulations, while welcoming their support

---

[10] Similar discussions are on-going within the INTRAC praxis project http://www.intrac.org/pages/praxis.html and among CDRA development practitioners and researchers www.cdra.org.za

- Finding arenas for revitalisation of the perspective within the project by, for example, organising regular consultations with participants and community members, taking on new challenges, giving time and space for reflection and self evaluation etc.
- Careful planning and preparation of leadership succession

These are some of the ideas that we have discussed, but there is a need for dialogue with other researchers to see how our findings can fit into the ongoing debate in the area of development cooperation and civil society capacity building. There is also a need for continued research to examine some of the findings more in detail.

Finally, we want to remind the reader about some of the common qualities of the projects seen as outstanding in our study. Perhaps, this could inspire other projects who are struggling to achieve social change for marginalised groups in various contexts. It is obvious from the summary table that most of the commonalities are rather "qualities" than "deliberate methods" that can be replicated. However, some of these qualities could probably be deliberately developed and nurtured.

Common strategies used	Common characteristics	Common basic factors
Interdependence, community involvement and participation	Creativity and innovativeness	Involvement of parents (people affected by the marginalisation) and their own desire for change
Networking and use of allies and partnerships	Shared value base - a strong belief that people with intellectual disabilities have a right to be part of society	Leadership with a strong vision who manages to inspire others and establish and maintain networks
Advocacy and awareness rising	Effectiveness	Staff commitment, empathy and satisfaction
Exposure and visibility in community and society at large	Courage/risk taking	Good management and professionalism
Constant capacity building of participants, parents and staff	Persistence, never giving up despite difficulties, trying new avenues	Community acceptance
Emancipation and self representation	Flexibility of activities according to changing needs and opportunities	Supportive local (and sometimes also external) networks

References

Aronsson**,** G. & Berglind, H. (eds.) (1990) *Handling och handlingsutrymme*. (Action and action space). Lund: Studentlitteratur.

Becker H., Geer B., Hughes E. & Strauss A. (1961) *Boys in white. Student culture in medical school*. Chicago: University of Chicago Press.

Farber, A. and Marcel, K. (1994) Jarent Power: Change Through Grassroots Networking, in Bradeley, V.J., Ashbaugh, J.W & Blaney, B.C. *Creating Individual Supports for People with Developmental Disabilities,* Paul H. Brookes Publishing Co., Baltimore.

Geertz, C. (1973) *The Interpretation of Cultures*, Basic Books, Inc., New York.

Goffman, E. (1990). *Stigma: notes on the management of spoiled identity.* Harmondsworth: Penguin Books.

Gustavsson, A. & Bergström, H. (2004) Pendlingen mellan olika tolkningsintressen (The dialiectics between different interests of interpretation). Published in S. Selander & P-J. Ödman (eds.) *Text och existence* (Text and existence) Göteborg: Daidalos.

Hannerz, U. (1992) *Cultural Complexity. Studies in the Social Organisation of Meaning*, Colombia University press, New York.

Hughes E. (1961) *Student´s Culture and Perspectives.* Lawrence: University of Kansas School of Law.

Kaplan, Allan (1999), *The Developing Of Capacity* Community Development Resource Association (CDRA), South Africa. Originally published as a Development Dossier by the United Nations Non-Governmental Liaison Service

Kesthely, Martha. *"Jag vill att ni hämtar min mamma... "Villkor för familjearbete för ungdomar inom institutionsvården* ("I want you to bring my mother here…" Conditions for family-work with youth in residential care). Dissertation from the Department of Education, Stockholm University.

Knoll, J.A. and Racino, J.A. (1994) Field in Search of a Home: The Need for Support Personnel To Develop a Distinct Identity, in Bradeley, V.J., Ashbaugh, J.W & Blaney, B.C. *Creating Individual Supports for People with Developmental Disabilities,* Paul H. Brookes Publishing Co., Baltimore.

Løchen, Y. (1965) *Idealer og realiteter I et psykiatrisk sykehus (Ideals and Realities in a Mental Hospital*). Universitetsforlaget, Oslo.

Parsons, T. (1964) Introduction, in Weber, M. (1964) *The Sociology of Religion*, Beacon Press, Boston.
Ramose, Mogobe (2002) The ethics of ubuntu. In Coetzee, P.H. and Roux, A.P.J. *Philosophy from Africa*. Oxford University Press.

Trankell, A. (1973) *Kvarteret Flisan* (The block Flisan). Stockholm: Norstedts.

Von Wright G. (1971) *Explanation and Understanding*. London:
Routhledge & Kegan Paul.
Weber, M. (1946) *Essays in Sociology*. Oxford University Press.

Weber, M. (1964) *The Sociology of Religion*, Beacon Press, Boston.

Weber, M. (1971) *Makt og byråkrati (Power and Bureaucracy)*. Studifakkal, Oslo.

Ödman, P-J. (2007) *Tolkning, förståelse, vetande* (Interpretation, understanding and knowledge) Stockholm: Norstedts.

National Research Teams – list of members

India
Team Coordinator
Dr. Suneeta Kulkarni - suneeta@vsnl.com
In collaboration with
Mr. J. P. Gadkari (PARIVAAR – NFPA)
Mr. Anil Joshi (PARIVAAR – NFPA)
Ms. Saswati Singh (PARIVAAR – NFPA)
Ms. Tulika Das (SANCHAR)
Dr. L. Govind Rao (NIMH)
Mr. T. Sivakumar (NIMH)
Dr. Meera Oke

Kenya
Team Coordinator
Ms. Margaret Morumbasi - m_morumbasi@yahoo.com
In collaboration with
Dr. Paul N. Mbatia - Chairman, Dept of Sociology, University of Nairobi
Mr. Samuel Tororei - Lecturer, Moi University Eldoret
Ms. Penny May Kamau - SHIA, Nairobi
Mr. Stephen Kaboi Burugu - KAIH National Chairman

Romania
Team Coordinator
Dr. Teodor Mircea Alexiu – West University – Timisoara - tmalexiu@socio.uvt.ro
In collaboration with
Ms. Laila Onu – Vice-president of Inclusion Romania
Dr. Aurora Toea – Director of C.R.I.P.S. - Bucharest
Dr. Radu Sergiu Ruba – Vice-president Romanian Association for the Blind Persons
Prof. Johans Sandvin, University of Bodö – Norway

South Africa
Team Co-ordinator
Ms. Washeila Sait – MPhil Disabilities Studies (UCT) - wbanien@iafrica.com
In collaboration with
Prof. Petra Engelbrecht – University of Stellenbosch
Dr. Theresa Lorenzo – University of Cape Town
Ms. Judy McKenzie – University of Fort Hare
Ms. Bernadette Liedeman – Disabled Children Action Group