

**STUDY OF THE PROCESSES AND METHODS USED
TO ACHIEVE IMPROVED LIFE CONDITIONS FOR
PERSONS WITH DISABILITIES**

**SOUTH AFRICAN
NATIONAL REPORT**



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A. BACKGROUND AND AIMS

1. INTRODUCTION AND AIMS

SHIA (Swedish Organisations of Disabled Persons, International Aid Association)/FUB (The Swedish National Society for Persons with Mental Handicap) and Inclusion International agreed in 1998 to support the collaborative project '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 persons with disabilities in general and children and adults with intellectual disabilities in particular.
2. To achieve sustainable improvement 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 that fight for the rights of children and adults with intellectual disabilities;
 - Forming and supporting Parent Mobilisation Action Groups (PMAGs); and
 - Using models developed in South Africa as a source of inspiration.
3. To study the processes and methods described above, as well as other similar initiatives so as to identify the most successful ways to achieve sustainable improvements in the conditions of children and adults with intellectual disabilities.

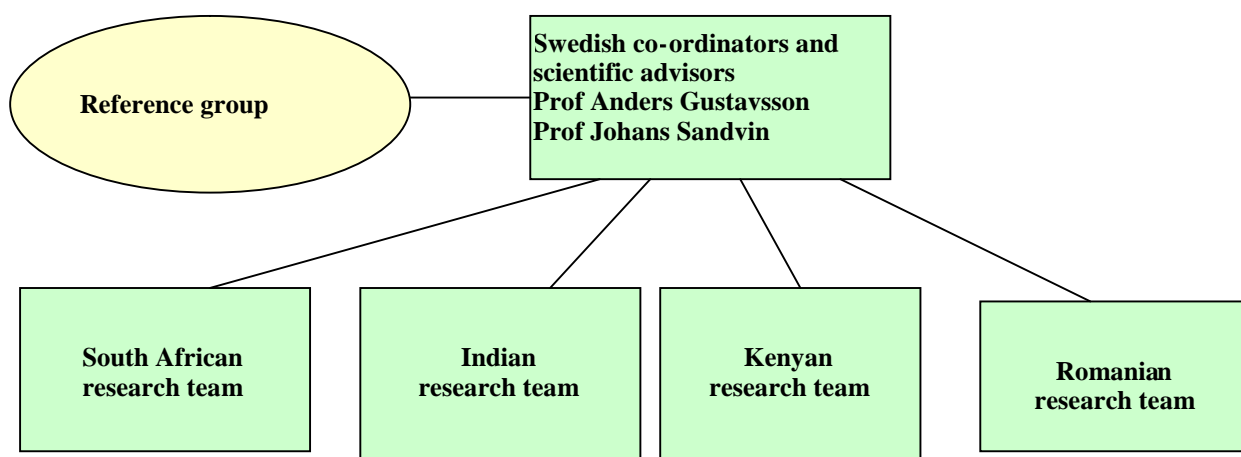
This study is the third and independent part of the project. It has been commissioned by Inclusion International and financed by SIDA (the Swedish International Development Agency). The aim of the study is to explore, understand and describe successful change processes and to learn from them. The following research questions have been addressed:

- Which projects resulting in sustainable improvements of life conditions for adults and children with intellectual disabilities can be found in the four countries?
- Which are the most strategic change agents: internationally, nationally and locally?
- Which methods are most effective in order to initiate and maintain processes of change?
- What other factors, deliberate project interventions, as well as contextual factors, are important to achieve positive change?

The study comprises four national studies from India, Kenya, Romania and South Africa. There will also be a final comparative analysis based on the national studies. **This report is the South African national study.**

The study has been guided by a Reference Group in Sweden¹. Research teams consisting of four to six persons have been established in each country according to the following guidelines:

- The teams should include one person, who has academically achieved a doctor's degree (or similar research background) to ensure the scientific level of the study.
- 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 organisation².
- 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 wider interest in the study.
- The team should have a team co-ordinator who is responsible for the actual planning and implementation of the study and for the timely reporting to the co-ordinators in Sweden.



In South Africa the following persons were on the research team:

Prof Petra Engelbrecht
Ms Bernadette Liederman
Dr Theresa Lorenzo
Ms Judy McKenzie
Ms Washeila Sait (National Project Co-ordinator)

In the study we used the Inclusion International definition of intellectual disability³:

¹Barbro Carlsson, chairperson and previously Secretary General of SHIA, Viktor Wahlström ex-president of Inclusion International, Fred Hed-dell, treasurer of Inclusion International, Tiina Nummi-Södergren of SHIA, Professor Anders Gustavsson, Stockholm University who has served as a scientific adviser and Annika and Lennart Nilsson responsible for co-ordination, administration and reporting of the study.

² Parivaar in India, Inclusion from Romania in Romania, DICAG and DSSA in South Africa and KAIH in Kenya.

³ Inclusion International information leaflet

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 1% and 3% of a population have 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 of the brain during pregnancy or at birth. Intellectual disability is normally not caused by social or psychological causes. Difficulties in learning and understanding lead to problems in school and working life and to difficulties in being

included 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 psychotherapies. 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 included in society.

In South Africa the approach to persons with intellectual disabilities and other disabilities (and in this study) is based on the Constitution of South Africa with specific reference to Section 9 (3) and (4):

3) The State may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnant, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief culture, language and birth.

4) No person may unfairly discriminate directly or directly against anyone on one or more grounds in terms of subsection (3).

2. BACKGROUND TO THE SOUTH AFRICAN STUDY

Over the last 20 years there have been substantial challenges to dominant perceptions of and attitudes towards people with disabilities. For much of the 20th century broad institutional understandings of, and responses to, disability have been dominated by a philosophical paradigm, which regards disability as residing within damaged bodies (medical model) (Kleinman, 1986). This paradigm tended to focus attention on the nature of the person's impairment and the degree to which this impairment may prevent the person from carrying out various tasks or participating in activities regarded as normal. The paradigm has been severely criticised for its inattention to the context of societal responses to disability which serve to systematically exclude and disadvantage individuals with certain disabilities. The emergence of the social model of disability (a politicised and critical societal contextualised view of disability) has demonstrated the 'disabled' identity to be one selectively, yet arbitrarily, inflicted on persons whose needs are systematically disregarded within the structure and functioning of most societies (Watermeyer, 2002:86-87). The approach thus focuses on the nature and organisation of society and its responses to people with impairments rather than on the nature and extent of the individual's impairment (Howell, 2005).

One aspect, however, distinguishes the general move from a medical to a social model of disability in South Africa from other countries, namely, the extent of political influences. For even in this field, the white-black dichotomy has resulted in extreme disparities in the support and general services rendered to the various population groups (Du Toit, 1996). The social model approach to disability in South Africa emphasised the government's policy to recognise, understand and address disability issues as a human rights and development issue, based on the principles of non-discrimination and equity that are entrenched in our national Constitution (Howell, 2005). Equally important to non-discrimination and equity in our Constitution is the recognition to the fact that people were in the past disadvantaged by unfair discrimination. The exclusion experienced by people with disabilities and their families is the result of a range of factors, including the political and economic inequalities of the apartheid system; social attitudes which have perpetuated stereotypes of disabled people as dependent and in need of care; and a discriminatory and weak legislative framework which has sanctioned and reinforced exclusionary barriers. The key forms of exclusion responsible for the cumulative disadvantage of people with disabilities are poverty, unemployment and social isolation. According to the Integrated National Disability Strategy (1997) poor people face a greater risk of impairment or disability. In addition, the birth of a disabled child, or the occurrence of disability in a family, 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 that there is an increase in families living at the poverty level *as a result of disability*. This phenomenon seriously hinders the development process. The International Labour Organisation (ILO) and the UN Development Programme (UNDP) state that a key indicator of poverty is the degree to which people are excluded from accessing basic goods and services. Poor people do not have sufficient income to purchase goods. They also live in underdeveloped areas where there is a lack of sanitation, water, electricity, health services, job opportunities and educational and recreational facilities.

People who receive social security benefits in South Africa tend to be totally dependent on them for their survival. The majority of people with disabilities, however, receive no grant at all. At the same time, an estimated 99% of disabled people are excluded from employment on the open labour market. The extremely high levels of unemployment amongst people with disabilities can be attributed to a number of factors, including low skills levels due to inadequate education; discriminatory attitudes and practices by employers; past discriminatory and ineffective labour legislation; lack of enabling mechanisms to promote employment opportunities; inaccessible public transport; inaccessible and unsupportive work environments; inadequate and inaccessible provision for vocational rehabilitation and training; general high levels of unemployment; the fact that menial labour is often the only option for poorly-skilled job-seekers; inadequate access to information and ignorance in society. The high level of functional illiteracy amongst disabled adults is a direct result of the lack of educational opportunities for children with disabilities, especially in rural areas. The result is low skills levels and a correspondingly limited access to employment opportunities. As a result the majority of people with disabilities who do have jobs often find themselves working in sheltered/protective workshops run either by the Departments of Welfare and Labour, by private welfare organisations or by disabled people themselves. Although the nature and scope of these workshops and self-help projects vary considerably, they do not provide people with disabilities and their families with sustainable incomes or opportunities for competitive economic activity (Republic of South Africa, 1997).

Under a democratic government, there has been a strong move since 1994 towards a social model of disability. This strong move is emphasised in the government's approach to addressing disability issues and involves recognising, understanding and addressing disability as a human rights and development issue, based on principles such as non-discrimination and equity entrenched in our Constitution (Howell, 2005). Equally important to non-discrimination and equity in our Constitution is the recognition of the fact that people were in the past disadvantaged by unfair discrimination. Unfortunately some new laws and amendments since

1994 (e.g. White Paper 6, Department of Education, 2001) still contain sections, which directly or indirectly lead to discrimination against people with disabilities. As a result, large sections of the legislative framework in South Africa still fail to meet international human rights standards and principles with regard to the rights of people with disabilities.

Legislation has contributed to the social exclusion of people with disabilities. First, legislation fails to protect the right of people with disabilities and, second, through legislation, barriers are created to prevent people with disabilities from accessing equal opportunities. Although there has, since 1994, been some attempt to identify and eliminate discriminatory legislation from our statute books, many aspects of past discriminatory legislation remain. In addition, some new laws and amendments contain sections, which directly or indirectly lead to discrimination against people with disabilities. As a result, large sections of the legislative framework in South Africa still fail to meet international human rights standards and principles regarding the rights of people with disabilities. One of the main reasons why legislative discrimination continues to take place is that discrimination is not always obvious merely by reading a statute. Problems often arise when the law or statute is applied. These include the way regulations governing specific acts are drawn up; the way acts and/or their regulations are administered; inappropriate and/or ignorant interpretation of the law and poor monitoring of the law. Although the rights of people with disabilities are enshrined in the Constitution, there is, as yet, no disability specific legislation (Howell, 2005; Republic of South Africa, 1997).

3. GENERAL RESEARCH STRATEGY

A basic assumption is that both living conditions of disabled people *per se* and changes in such living conditions, to a large extent, depend on contextual characteristics such as the national economic conditions, rights and obligations linked to the citizenship, cultural representations and customs, amongst others. As a consequence processes of change affecting the living conditions of people with disabilities are likely to differ from country to country and action that proves to be effective for promoting change in one country is not necessarily the most effective in another country. This has important consequences for our study.

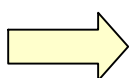
First, our understanding of the processes of change and improvement is better facilitated by rich contextual data than by comparisons with other similar interventions aimed at social change. As a consequence, extensive case studies are likely to be more helpful than broad comparisons of many different cases. Therefore, we decided to limit the study to three successful projects

resulting in improved living conditions of people with intellectual disabilities in each of the four countries.

Secondly, in order to investigate and understand the dynamics of specific processes of change, the process has to be studied in its own unique national and local contexts. This means that the projects will be studied in their particular historical, national and cultural contexts and that the comparative phase of the analysis is introduced in the final analytical step to explore interesting similarities and differences in the basic factors of change identified in each individual change process. In short, the study starts with a rather open exploratory approach aimed at increasing our understanding of successful projects in the four countries and identifying basic, important factors promoting change and ends with a more comparative approach exploring similarities and differences between the three processes of change analysed by each national team.

Because of the big contextual differences between and within countries, the research methodology has been developed in a participatory process where each national team has played an important role.

The design of the study is rather open and sensitive to the approaches that the national research teams find most productive. However, identifying differences and similarities in change processes in the four countries requires a common basis for the selection of the cases.



The examples of change processes to be selected for the case studies should be called **PROJECTS**. A project is a deliberate effort to achieve positive change in the situation for persons with intellectual disabilities. A project has a starting point and an end point.

It was also agreed that the following **four criteria** should guide the selection process:

1. A substantial impact on the quality of life of persons with intellectual disabilities

The project must have impacted positively on at least four of the quality of life (QOL) domains in order to be selected (or had an exceptional impact on one of them). The following IASSID consensus quality of life domains were used as a common frame of reference⁴ to describe quality

⁴ The Reference Group has examined different instruments and more general points of departure that could be used to evaluate the impact of the successful projects. Different tools have different benefits and disadvantages. As we are about to study relative changes in various cultural, political and economical settings, we need to use a tool that is flexible, easy to use and that is not relating too detailed and context-bound measurements of life conditions. We

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, purposive activities, assistive technology;
- **Physical well-being:** health care, mobility, wellness, 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.

To make the quality of life domains more concrete and possible to use as selection criteria for the national teams, local interpretations were required. Based on interviews with parent groups and groups of persons with disabilities themselves, each national team documented practical, concrete 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 quality of life domains, was developed in each country. An additional domain was created for the African context, namely, interdependence: meaning the supportive mechanisms and mutuality within the home and within the broader community.⁵

2. Sustainability

The project must have been in operation for more than two years. The project must have less than 50% of its operations financed by foreign resources/funding 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.

need a qualitative instrument that can capture the improvements on both individual and society levels from a user perspective. In this particular study we give priority to strategies that are likely to picture the dynamics of the changes in an empirically sensitive way. While being aware that quantitative instruments generally are preferred when making 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. This means that we will use the indicators primarily as a list of qualities or criteria. We do not think that it would be possible to carry out precise measurements of individual person's quality of life or changes in their quality of life.

⁵ The national QOL instrument is attached in Appendix 1.

3. Significant impact (substantial coverage)

The project must have a significant impact in the community (nationally or locally) and not only be limited to service provision for a small group.

4. Interesting

The projects must be interesting to study.

- The projects should be different (national as well as local initiatives, government as well as NGO initiatives should be considered).
- The projects should be innovative.
- The projects should provide many useful lessons.
- One of the projects should be implemented by an Inclusion International national member organisation or its affiliates (provided that the other selection criteria are fulfilled).

These selection criteria were developed and approved at a joint meeting of national co-ordinators, Swedish co-ordinators and scientific advisors in June 2004.

Invitations for nominations were distributed amongst 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 motivation and an assessment in relation to the selection criteria. The reward for participation in the study was the prospect of having your project exposed in an international publication. (In South Africa a total number of six projects were initially nominated, and two nominations were received at a later stage. The presentation of the edited nominations of all projects meeting the selection criteria is published as a special appendix to this national report⁶.)

The nominations were scrutinised by the national teams and in South Africa by an independent panel of experts and amongst those fulfilling the first three criteria, the most interesting were chosen. An exceptional achievement in a difficult context and interesting and different approaches were factors that influenced the final selection. The decision was based on a consensus in the South African team. The projects and the motivations for the selection were documented and presented at a joint meeting of the national co-ordinators, the Swedish co-ordinators and scientific advisors in January 2005. At this meeting the selection process was discussed and approved.

⁶ Appendix 2

4. SELECTION OF SOUTH AFRICAN CASE STUDIES

The South African team, having finalised their QOL domains and criteria, as well as the invitation letter for participation, sent out invitations for participation in the study in mid-September 2004 to various stakeholders, government structures and organisations and requested the return of completed questionnaires by the end of October 2004.

To encourage a wide and varied spectrum of nominations for participation in the study, invitations were sent to various disability organisations, government authorities and structures and various other stakeholders considered relevant to and friends and allies of the disability movement of South Africa.

Regarding the government sector, invitations were sent to different national departments including the department of Health, Education, Social Development, Justice and the national departments dealing with rehabilitation services. Within governmental structures, invitations for participation were sent to the Human Rights Commission, the Office on the Status of Children, the Youth Commission, the Gender Commission, government structures in the National Assembly that deal with issues of disability and child health and welfare issues, as well as all nine Provincial Offices on the Status of Disabled people located within the Provincial Premiers' Offices. The national offices of the fourteen disability-specific sectors in the disability movement of South Africa were also invited to nominate their projects located at provincial level throughout the nine provinces of South Africa.

A time frame of one month was provided to enable invitees to respond to the invitation and questionnaire extended. The due date, 30 October 2004, yielded three responses. Further follow-up communications, reminders and extensions yielded a further two responses. Personal support and communications to two specific organisations yielded one more response. Despite the follow-up communications, reminders and personal support provided, the total nominees for participation thus far resulted in six responses for participation within the study.

In trying to ascertain what could possibly be a barrier to participation, we concluded that the possibility might be that the information required in the questionnaire itself may have been regarded as overwhelming or too daunting for most invitees. Some examples of the reasons given for not being able to participate in the study were:

‘Thanks for the information. I don’t think I have the necessary knowledge to answer this suitably. Sorry.’

‘Thank you for the invitation to participate. Although Cheshire Homes does provide services to people with intellectual disabilities, we do so in an integrated environment and thus we do not have case study material specific to their disability.’

Amidst disappointment at the poor total number of nominations received to participate, the team decided to proceed with the selection process of the six nominations received initially. A total of four people were approached for participation within a selection committee for the small amount of nominations received, two were from governmental structures and two were from academic institutions. A total of three persons out of the identified four were people with disabilities. Only two people indicated their willingness to participate on the selection panel, and both were located in academic institutions.

To assist and guide the assessors with their selection process and decision-making of the six projects presented, a measurement tool of impact on QOL on persons with disabilities was developed in accordance with the agreement in the International Group for assessment of project arguments for participation. This tool included areas such as:

- QOL domains and specific criteria;
- Characteristics that exemplify these criteria;
- Effective programme approaches that realise these criteria;
- The level of impact on the lives of the individuals or project according to the measurement scale 0-2.

In addition to this tool, background information on the study, together with the criteria brief for the selection process, were provided to the two assessors.

The assessors were then supplied with information of the self-nominated projects.

TABLE 1: SELF-NOMINATED PROJECTS

PROJECT NAME	INSTITUTE/ORGANISATION	TYPE OF PROJECT	LOCATION
Happy Home	DICAG Umtata	Multi-purpose project	Eastern Cape
Astra Centre	Disabled adult organisation	Sheltered employment	Western Cape
Classic	Service provider organisation	Learner educational assessment	Gauteng
St Joseph Marist College	Mental Health Project	Special needs education unit	Western Cape
Intellectual Quality Lifespan Development Project	University of Stellenbosch	Support project to learners with Downs Syndrome	Western Cape
Sunfield Home Logwood	Service provider organisation	Residential centre	Gauteng

The projects represented a wide variety of interests related to processes and methods used to improve the life conditions of persons with intellectual disabilities.

The assessors were asked to analyse the arguments for participation within the study as represented by the self-nominated projects, and to use the information provided with specific reference to the selection criteria for participation in conjunction with the measurement tool. The assessors were also asked to provide a motivation for their selection of choice and to further grade these into first, second and third choices.

There was a good measure of agreement in the selection of choice of projects between both assessors. The only difference in their selection was noted in the positioning of their choices in terms of priority.

TABLE 2: CHOICES OF THE ASSESSORS

POSITION	ASSESSOR ONE	ASSESSOR TWO
First choice	Happy Home	Astra Centre
Second choice	Astra Centre	St Joseph Marist College
Third choice	Quality of Lifespan Development Project	Happy Home

Both the assessors provided good motivational arguments for their specific selection and choices of prioritisation made. A consultation was held with the team members to make a final decision on the selection. Since both assessors agreed on two projects and presented good arguments for both these projects despite their difference in prioritisation, it was agreed that these two projects, Happy Home and Astra Centre, would be part of the first phase of data generation for the study. It was also decided that the remaining four projects would be re-included into the selection pool once more nominations have been solicited for participation.

Both Happy Home and Astra fitted the selection criteria and both projects displayed elements of specific innovativeness in their project approach manner to improve the QOL of persons with intellectual disabilities. Based on this decision, the team decided to proceed with the implementation of data generation and started on the project of Happy Home, Eastern Cape.

A set of open-ended questions was developed and an agreed to interview schedule, between the project co-ordinator and researcher, was developed. One of the most frustrating areas of the first phase was the poor response from the disability sectors, government structures and departments and other stakeholders. Because of our diverse background, there was indication of huge barriers experienced in terms of self-assessment of projects. In addition to this, there was the need for the questionnaire to be translated into all eleven languages, which proved to be an impossible task, given the short time frame for implementation. We had to rely on organisational directors to interpret the questionnaire for their constituencies in a way that was easily understood.

Two late nominations were then received: one from the Association for the Rehabilitation of Disabled Persons (Eastern Cape); and the other from Whizz Kidz (KwaZulu-Natal). After extensive consultation at national level, the decision was taken to add Whizz Kidz to the selection, together with Happy Home and Astra. Two of the major players in the study, DICAG and DSSA, did not respond to the call for nominations as expected. It was later learned that DSSA does not have self-help projects on the ground, but leaned towards service provision.

DICAG, on the other hand, informed their council, but none of the council members who represented their provincial structures responded.

5. RESEARCH DESIGN AND METHOD OF DATA GENERATION IN SOUTH AFRICA

Research design

According to Babbie and Mouton (2001:74) research design is a plan or structural framework of how the research will be conducted in order to answer the research problem. In this instance, a mixed method design that included both qualitative and quantitative features was used in order to evaluate the selected programmes/projects (Gill, 1999; Lefort and Fraser, 2002; Mertens, 1999). Evaluation research is the systematic investigation of the merit or worth (effectiveness) of an object (in this instance a project/programme) for the purpose of reducing uncertainty in decision-making about the effectiveness of the object. In order to answer the research questions as discussed in the first section of this document and evaluate the impact (as discussed in 1) and outcomes (as indicated in 1), at least three pieces of information were needed: observations of performance on the dependent variable(s), in this instance QOL domains and criteria that serve as an indicator(s) of the expected result (impact on persons with disabilities), implementation evaluation information that can attest to what happened to the participants and contextual information that could serve as rival explanations for observed changes (Mertens and McLaughlin, 2004).

An interpretivist/social constructivist framework, which incorporates participatory research elements and takes as point of departure the fact that reality is socially constructed, enabled the evaluators to systematically demystify the structures and processes, which create disability (Schwandt, 2000; 2004).

According to Potter and Kruger (2001) most evaluation researchers in South Africa tend to draw from interpretative and participatory approaches to evaluation: given the context of social development and the social disparities and poverty that characterise societies in many areas of the African continent, it is likely that researchers will opt for some form of participatory evaluation. This approach has particular relevance to working in community settings in Africa (Potter and Kruger, 2001:206).

The evaluation approach within an interpretivist/constructivist framework in South Africa's part of the project was based on the following two assumptions made in current literature (Schallock,

1996; Zekovic and Renwick, 2003) on QOL conceptualisation and assessment:

- QOL is a multi-dimensional and complex phenomenon that results from complex person-environment interaction and consists of eight core dimensions.
- Both objective and subjective measures should be used for evaluating QOL and specific attention needs to be paid to who is qualified to speak for the disability community or individuals from that community when the evaluators collect the data. Furthermore, the disability perspective of staff and consumers must be included in an authentic way and individuals with disabilities must be free to convey their views in their own voice (researchers should attempt to understand the complex world of lived experience from the point of view of those who live it, Mertens, 2005).

Data generation approaches therefore used both personal appraisal (interviews, observation) and functional assessment measures reflecting four or more of the eight core dimensions.

The units of analysis were the three case studies of the selected programmes/projects that involved intensive and detailed study of the specific programme/project as an entity through observation, interviews (as discussed below). Quantitative and qualitative methods were combined to capitalise on the strengths of each and ensure higher quality of data (Babbie and Mouton, 2001). Qualitative methods allow for more probing and in-depth exploration of views (attempting to understand QOL from the perspective of participants, capturing the 'insider' perspective of participants) while quantitative methods lend themselves to standardisation and application across many sites. To evaluate a specific case (programme/project) in-depth, information on the following was collected: the nature of the project: its historical background; the physical setting; other contexts such as economic, political and legal; those informants through whom the programme can become known in-depth; as well as to what extent the programme succeeds in impacting on the quality of life of persons with disabilities.

Data generation

A literature review informed the researchers of previously conducted studies on QOL and successful practices in this regard as well of quantitative methods on the measurement of the impact on QOL of persons with disabilities. Qualitative methods that were used to generate data included observation, interviews and documents. Observational data represent a first hand encounter with the phenomenon of interest, in this instance the context, participants and role-players in the selected programmes rather than a second hand account obtained in the interviews. Field notes were used to capture observations during and after observations. Interviewing in

qualitative investigations is more open-ended and less structured as it is assumed that individual respondents define the world in unique ways (Merriam, 2002). In this instance a semi-structured strategy was used in which the interview was guided by a list of questions or issues to be explored as identified in the initial paper evaluation of the short listed projects/programmes. This personal appraisal strategy also addressed the subjective nature of QOL, typically focusing on evaluating how satisfied the person with a disability is with the different aspects of life. It also addressed the functional appraisal of parents, community members and staff of the outcomes of these programmes. In accordance with Merriam's view on documents as a qualitative research method (Merriam, 1998), the term 'documents' was used as an umbrella term to refer to a wide range of written, visual and physical material relevant to the evaluation of the selected programmes.

Data analysis strategies

The constant comparative method developed by Glaser and Strauss (1967, in Merriam, 1998) was employed to analyse the qualitative data. Interviews were read as a whole (in a specific programme) while notes were made of the most striking aspects related to the purpose of the evaluation in the margins. In this way one unit of information was compared with the next recurring regularities in the data will be identified. Before moving to the next transcript, margin notes were reviewed and consolidated. After working through all the data, themes were constructed by grouping those comments or units that seem to belong together. Regularities became the themes into which the succeeding themes were sorted, and this process was continued until a point of saturation was reached (Swart, Engelbrecht, Eloff, Pettipher and Oswald, 2004).

The following strategies were used to enhance **validity and reliability** (Merriam, 1998; Babbie and Mouton, 2001; Neuman, 2000):

- Triangulation: multiple researchers and multiple sources of data and methods of data collection to confirm the emerging findings;
- Member checking and peer examination: discussing the data and tentative interpretations with the international research team;
- Multi-site designs: using several case studies with differing contexts to maximise diversity.

Ethics

Ethics in research is an integral part of all research planning and implementation processes and in this instance obtaining the fully informed consent of all participants and guarding the privacy and confidentiality of the participants was a priority. Furthermore, all participants were debriefed after the evaluation was completed and results discussed with all involved. When participants are people with disabilities special precautions should be taken to protect them from risk and recommended strategies included consulting with experts and members of the vulnerable community to determine appropriate strategies (Mertens and McLaughlin, 2004).

Furthermore, the researchers faced social equity issues in the sense of ensuring all participants and other stakeholders in the evaluations equitable assignment of treatment and equitable access to the evaluators' time and attention. Evaluators considered the diverse nature of participants' and stakeholders' approaches, bearing in mind the concomitant issue of conflicting perspectives of and the multiple social meaning that may be attributed to the evaluations (Potter and Kruger, 2001).

Limitations

In the disability arena alone, South Africa has a wide range of services, organisations and governmental agencies that deal with issues of disability and more specific childhood disabilities. Within government these relate both to national and provincial structures, the same set-up accounts for organisations and associations within the disability field. In total, there are forty-seven listed entities dealing with issues of disabilities at national level. The majority of these entities have provincial structures that in turn have structures at local municipal levels. It was very disconcerting to note that we received a poor response for self-nominated participation within a study that aims to determine the essence of processes and methods used to improve the quality of life of people with disabilities, and more specifically, people with intellectual disabilities. Furthermore, it turned out that the selected project also included challenges to the sustainability of the project and it was questioned if the selection criteria had been fulfilled. After analysing these challenges it was found that they never the less provided some very interesting lessons. By describing both positive and negative sides of the cases and analysing the factors behind these characteristics – we could cross-examine some of our findings.

B. CASE STUDY SUMMARIES

1. ASTRA PROJECT

Description

Astra Centre 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 as a means to add value to their lives through meaningful employment. The Organisation of Rehabilitation and Training (ORT) started the project fifty-four years ago, under the leadership of the late Dr. Louis Mirvish. He identified the need to create a centre that would provide employment for Jewish men and women who were unable to work within the open labour market because of their different individual situations. The centre started off with one sewing machine, one worker and a loan of 200 British pounds.

Astra's aim is to develop the potential of people with disabilities through the provision of meaningful employment that could add value to their lives and bring about an improved quality of life. In addressing this aim, Astra develops and provides individualised programmes and services by utilising an interdisciplinary approach that is based on Jewish principles and values. The specific focus of the programmes is on individual strengths, needs, abilities, interests and desires.

Located at the foot of Table Mountain within a suburban/central business district, the activities of the project happen within an old double storey house with small rooms that serve as departments for the different activities of the Jewish Sheltered Employment Project (JSEC). These departments are:

- Weaving;
- Needlework;
- Artwork;
- Woodwork;
- Contract works;
- Marketing and sales.

In recent years they have added three more projects, two of which operate from the Astra project premises. These are the Coffee Time coffee shop/small restaurant that boasts a thirty-two-seater capacity. The other is the Giftime project, which is in partnership with the Bnoth Zion organisation and provides a gift-wrapping service to the local, as well as international and E-

commerce community. The Supported Employment Project is a service that provides assistance to disabled members who have potential to work within the open labour market. Services include assessment, work preparation, and job counselling, job placement and support. In addition, the employment projects, Astra has over the years acquired two private houses to accommodate their group home projects. Currently they have a total of seventeen members who reside within their Rose Court House and Vriende House group home projects. These four projects fall under the umbrella of the Astra project.

A director oversees the day-to-day management of the project, and a social worker/works manager oversees the staff complement that comprises professional staff, supervisors, machinists and domestic staff. The project has a large component of volunteers whose intake is managed by the social worker/works manager. These volunteers assist workers and supervisors on a rotational basis for at least two hours daily.

Resources to be found in Astra are wide and varied. Although they do not have a specific donor, their sponsorship is mainly derived from the Cape Jewish Welfare Council, a small but long-standing government subsidy, individual bequests and donations, and revenue derived from sales and business activities.

Astra also has a wide network that assists with resource building and the sustainability of the project. Their network base is mainly made up of organisations and institutions from their own community such as the Union of Jewish women, Herzlia schools and Glendale Home amongst others. Other organisations include Ikamva Labantu. They operate within disadvantaged communities, and other sheltered employment organisations such as Oasis Workshop within the broader community of Cape Town. The Jewish community has thus far been very involved and supportive of Astra and regularly visits and interacts with the project. The implementation of Gifttime and Coffee Time has brought about greater interaction with the general community of Cape Town as well as other national and international visitors.

The project is registered with the Cape Jewish Welfare Council as a welfare/community organisation that deals with sheltered employment for Jewish disabled people. It is also registered with the Western Cape Social Development department as a non-profit organisation.

Astra is managed through a three tier governance leadership structure: the executive committee focuses on the administrative issues of the project; the medical committee focuses mainly on the professional medical service needs of project participants, and also provides the latest information

and developments on the treatment, care and support of intellectually disabled and psychiatrically ill people; and the management complement is lead by the director whose staff consists of various professionals with different levels of expertise under her direct supervision.

The South African Jewish community is deeply attached to traditional values and has strong bonds with the State of Israel. Consequently, the Astra project practises their principles and a general approach to life founded on Jewish values and principles. Although the community of participants within the project is strictly Jewish, there is a diverse cultural and religious grouping of employees within Astra. An environment of tolerance, respect and acceptance has been created to accommodate the diversity that is found in the project. This is evident in how the religious and cultural backgrounds of employees are acknowledged, when for instance, special days for the Christian and Muslim faiths are recognised and respected.

Analysis

The success of the Astra project under the present leadership structure is ascribed to their innovativeness to transform their sheltered employment project to a place where meaningful employment is provided that enables participants to earn an income and at the same time add value to their lives. Coupled with additional income generating projects such as Gifttime and Coffee Time, Astra not only generates revenue for sustainability, but also has changed the perception of the project in the community in that the focus on what Astra's core activities have shifted through the awareness that it raised.

Astra's transformation over the years contributed to how the participants experienced their project. There is far more emphasis on the development of individual potential, recognition of the uniqueness of each individual and ensuring human dignity through acknowledgement of individual rights and recognising the need to create enabling environments to foster a sense of self-worth and dignity. Through the progressive implementation of these principles, Astra has opened up new challenges for their participants to overcome. Individual participants knowing that they have the trust and faith of their supervisors and co-workers in their ability to do their jobs successfully take up these challenges.

The unique and highly skilled staff at Astra is another contributing factor to the success of the project. Understanding and patience towards the participants are applied by the managers, supervisors and other staff and form the basis for the participants to gain and regain their self-confidence in their ability to work and be successful at it. The interaction between staff and

participants, and amongst participants in the project have made a positive impact that creates an environment where the place of work has become a home away from home for all.

Another contributing factor to the success of Astra is the manner in which an interdependent environment has been created within the project. This interdependence forms the axis of Astra's continued activities and existence. There exists a great deal of interdependence between staff and participants, between participants and also between the various departments and income generating projects.

Astra's acknowledgement of the power of interdependence amongst people to survive and bring success to life and to their projects for the attainment of sustainability has been the influential factor in the success of the project. Their pro-active approach to transformation ahead of government requirements makes this project extraordinary. Positive elements that further increases the success of Astra is their vast networks both nationally and internationally and the unfailing support that they have from most members of the Jewish community.

Despite the success that Astra has been able to instil within their project, there are a number of threatening elements that remain challenging to the project. One of the major challenges that confront Astra is the creation of the project as a place of pure employment and business interest. The nature of Astra's participant component requires that the interest of the participant is paramount to the production process of the project. Therefore, it challenges Astra to find a balance between therapeutic and employment aspects that do not undermine the confidence of the participants and employees, and the relationship between them, and the business identity that Astra is currently creating.

Astra is also further challenged by tensions created between adhering to government policy and what the project intended, such as their exclusivity. Their exclusivity at present presents a barrier to full participation within the Governments financing policy. This requires that some measures be undertaken for Astra to engage fully within Government policy. Presently, Astra is enjoying some level of sustainability. However, this sustainability is threatened by a number of factors such as insufficient subsidy from Government, their struggle to get buy in from the Provincial department of Social Development Services as a transformational consultant; the need to ensure that the interests of the participants take precedence over contract opportunities, as well as the substantial number of emigrants from South Africa, which decreases the potential donor income to the project.

Paramount to all of this is the downside of interdependence. Interdependence has created a strong sense of reliability of the project components on one from the other. Astra has created a strongly woven supportive network for their project, thus binding activities and resources with each other. This supportive network needs to be maintained through human resources and funding, and more specifically needs the type of employee that is able to work with special needs people such as Astra's participants. If these elements are not maintained, they will affect and weaken the net, which might undermine the improved level of quality of life of the participants and the confidence and security that the employees currently experience.

Providing services to people with intellectual disabilities and psychiatric illnesses with the aim to improve their quality of life requires a unique approach. Astra, in this regard has the following lessons to offer:

- Focus on the ability of the person involved within the project, identify creative means to explore and develop their potential.
- Bring in professional skills to assist in training and building the skills of participants.
- Appoint people who are willing to commit themselves; have a passion to share their specific expertise; are willing to become team players; are willing to help those less fortunate than themselves, and can maintain good interpersonal relationships.
- Create a positive and supportive environment that encourages the co-operation of the participants, and have a holistic approach in the development of the participants and the project.
- Be informed about government legislation and policy; be proactive in terms of what it requires and what you can offer.
- Be creative; find ways and means to involve the local community spontaneously to bring across awareness and positive messages about persons with mental and intellectual disabilities.
- Create a network base for the project that is reliable and with whom meaningful interaction and exchange can happen.

As discussed earlier, Astra project is clearly driven by interdependence. This is demonstrated in how the project programmes interact with each other, the manner in which the participants interrelate with one another and the employees within the project, the way sustainability of the project is interdependent on community involvement and the way the leadership structures interact with each other. Although Astra is a relatively old project, it has demonstrated that over

the years it has made considerable impact within the local and international communities, and with that has managed to sustain itself with primarily local resources. The project has definitely managed to improve the quality of life of its participants as is evident from the data analysis. The project also demonstrates that changes and improvement in the quality of life of persons with disabilities cannot happen overnight, but needs to happen progressively. There are many important and interesting lessons to derive from this project. What remains is for Astra to find a way to share their expertise and knowledge with other organisations of the same ilk in communities that are less fortunate, as a means to give deeper meaning to their attempts at and initiatives for transformation, and the improved quality of life for all persons who are intellectually disabled and psychiatrically ill in South Africa.

2. HAPPY HOME PROJECT

Description

Happy Home is a self-help project for parents of children with disabilities. It is situated on a smallholding in a rural area of the Eastern Cape in South Africa. The area has a high level of poverty and unemployment. Most people in this area rely on meagre sources of income derived from pensions, social grants or migrant labour. The eight-year-old project is the initiative of Mrs Vuyelwa Duma and is the direct result of the formation of Disabled Children Action Group Mthatha. It was brought about through the empowerment programmes offered by Disabled Children Action Group, the national parent organisation.

The project caters for 77 children, has a voluntary staff compliment of 12 volunteers including 2 male supervisors for the poultry and agricultural farming projects, 2 cooks, 3 caregivers, 1 pre-school teacher, 1 receptionist for the administration area, and 3 members of the sewing project.

Governance of the project is implemented at three levels: the board of trustees whose function is the custodianship over the property which houses the project; the board of directors that boasts a multi-disciplinary team whose function is to provide guidance in the planning and execution of functions tasked to the parent committee; and the parent executive committee structure whose function is to ensure that the objectives of the project are implemented and that the day-to-day activities of the project are planned and run smoothly. These three structures meet regularly. Staff meetings are held on a monthly basis. Children at the project also participate in these meetings when their specific input is required on issues that affect them directly. An accredited bookkeeping firm manages the financial affairs of the project. The project is registered with the

provincial department of Social Development Services as a non-profit organisation and is exempted by the South African Revenue services from tax.

Happy Home anchored their humble beginnings in the belief that all children, including disabled children, have the right to a life that fulfils their basic human needs, and that children have the right to status and a quality of life that is equal to and on a par with that of their non-disabled peers. This foundation is further strengthened by the belief that given the opportunity, and if the parents of disabled children are informed and empowered about issues of disability, they themselves would be the best agents for change to improve the quality of life of their disabled children and that of the family as a whole. The children themselves therefore become the best self-advocates for their own empowerment and improved quality of life needs.

The main objective of the project is to provide opportunities to access education to educable moderately disabled children. The specific focus is on disadvantaged disabled children and their families in the rural areas of Mthatha. By providing skills development opportunities to the youth and their mothers, the provision of hostel facilities to enable the children better opportunities to access formal special education in the city area; the empowerment of parents through the provision of information for advocacy and development purposes, are all means to which the project aims to contribute towards improved life conditions for the children and their families.

To realise this objective, the project offers programmes such as early childhood development, stimulation and education for children with varying degrees of disabilities; business skills training for disabled youth; income-generating skills training for mothers and hostel facilities. The project has outreach empowerment and development programmes in the villages and districts that surround Mthatha.

These programmes are implemented from the smallholding that is located in a suburb of Mthatha. The previous owner who came to know about their plight to acquire suitable property for the implementation of the project made the acquisition of the land and its properties possible. With the help and support of the governing structures and their networks, the assistance of former President Nelson Mandela (Madiba), and the financial assistance and guidance of SANLAM (a life insurance company), the property was acquired in 1998. The acquisition of the property marked the official existence of Happy Home. Over the past eight years the project has developed into a dynamic income-generating project with the input and assistance of the children in the project, the parents, community and local business people and members of the governing structures. Today the project boasts large grounds on which several buildings dot the entire area

of the grounds, save for the space that is allocated for the food gardening, the grazing land and the football pitch.

Entrance to the premises is granted through a security-controlled gate. A long driveway leads up to the administration block, past well-kept gardens displaying rural ploughing equipment. Adjacent to the administration block is the original farmhouse, which houses the sleeping quarters for the young girls, smaller children and caregivers. It also accommodates the dining and lounging areas for the children. At the far end of the back garden are the sleeping quarters for the boys and the male help, the newer buildings that house the income generating projects, the early childhood development section, the board rooms, new kitchens and store rooms. The sprawling lawns that surround the buildings have a pool much in need of repair, and outdoor play equipment and garden furniture arranged to encourage leisure activities. Well-laid out and accessible footpaths connect the buildings and activity areas. Renovations to ensure optimal accessibility are ongoing.

The project derives its financial resources for self-sufficiency and financial sustainability through various means. School fees and membership fees are one source; while the sale of garments made by the sewing group, as well as surplus eggs, milk and vegetables produced through the farming activities are another source of income. The youth at the project, who have been taught business skills, are primarily responsible for the sale of produce to local food markets and hospitals. The financial resources for the upkeep and maintenance of the physical structure are provided through their primary donor SANLAM, with some support from local business communities and other community-based structures.

The project has networks within the community that assist the further development and upkeep of the project infrastructure. For instance, the local veterinary doctor provides free veterinary services to the cattle of the project. The traditional leaders' forum in government provides farming equipment. As for the health needs of the children, two local general practitioners who own private health practices treat the children free of charge when necessary. The project also has a good networking relationship with other community-based organisations. There are important networks made with respected and well-known members of the community such as traditional healers, members of the local judicial system, and Madiba who is one of the most ardent supporters of the project. With the additional networks formed in the church and business communities, the networks collectively form a supportive structure for the ongoing development of the project.

The social structure of Happy Home project is entrenched in cultural and social practices that are to be found in rural community living. This includes the culture of *Ubuntu* whose meaning translates to the interdependence of the collective existence of the community. Communality as an ethic comes through in the degree of the social responsibility that members of the community feel towards each other. Within the project, social practices as determined by traditional culture also contribute towards the way that the children are respected by each other and how they are cared for. For instance, eating arrangements for lunch and dinner are separate for the youth and the younger children. The youth are further separated in terms of male and female seating arrangements. The separation of eating arrangements is an indication of respect and acknowledgement of their status as young men and women in the project.

Analysis

The success of Happy Home project is underpinned by how the project has thus far managed to overcome the challenges that face the development of disabled children and their families. These challenges were mainly centred around the poor treatment of the children in the community, the experience of sexual abuse by some of the children, the negative attitudes and cultural belief systems towards disability, the non-acceptance of children as members of the community, and the subsequent barriers experienced to access appropriate services such as education, social services or information. Children with disabilities in the rural areas of South Africa are particularly challenged because they are a large grouping whose needs have generally gone unnoticed. There is widespread bias and exclusionary practices that affect the educational possibilities of boys and girls with disabilities (HSRC, 2005). Life before Happy Home was therefore no different for most of the children. Their lives in the villages were fraught with the struggle for acceptance and acknowledgement as members of their communities and society as a whole. Despite the culture of *Ubuntu* being practised in the majority villages, most of the children experienced life in the villages on the periphery of *Ubuntu*. Attitudes in the villages were particularly poor and their treatment in the communities was appalling.

The innovativeness of the project lies in the strategies used to overcome the challenges experienced as a collective. For instance, Biblical strategies such as prayer gatherings and night vigils as a way of passive resistance against injustices and to overcome barriers to accessing social security were used. The International Day of Disabled people (3 December) became an opportunity to raise awareness on the rights of disabled children and adults. The identification of common problems experienced, as a collective became a strategy and platform to harness

membership and mobilise community support. Through educating the parents on issues of disability, the project brought parents and children together. By setting up community-based structures aimed at addressing childhood disability issues, the project has managed to make disabled children part and parcel of their communities.

The impact that the project has on the lives of the people engaged in the project is fundamental in that it changed the life course of all concerned. For the children, it brought about many significant and empowering changes to their lives. For instance, being part and parcel of all activities that happen at the project and taking part in decision-making on issues that effect their lives contribute towards improvement in self-determination; personal development; interpersonal relationships and their general emotional well being. For the youth in particular, being part of income generating activities and business development has greatly contributed towards their own material well being, as well as that of their families. Through their business activities, socialisation opportunities have increased, thus raising awareness of their existence and their profile in the business community and community in general. Being part of the project has also helped towards obtaining a grant for the children. This plays a significant role towards their material well being and in helping to provide for their families.

The environment of equality that has been created for the children has unleashed the need to show and demonstrate their potential. The nurturing environment of love, understanding and care is a contributing factor that has brought about a positive sense of emotional well being and a sense of belonging. The children have begun to have some concept about their rights and clearly enjoy being consulted on issues pertaining to the decision-making processes of the project.

The positive impact of the project extends beyond the lives of the children and their parents, to the affiliated members and members of the community. The awareness of the rights of disabled persons within the community that the project has raised is evident by the testimony of the adults within the project, the affiliated members and members of the broader community. All attest to the respect that disabled people and their families now enjoy within the community.

The success of Happy Home lies in the manner how the project has thus far managed to construct a conducive environment that surpasses the selection criteria stipulated within the terms of reference for participation in this study. The improvement of quality of life as far as the children are concerned, could not have taken place without the unflinching support of the primary donor SANLAM; the unselfish love and care provided by the staff; the display of commitment and will of the board members to bring about change for the children; the ardent support of the project by

respected and well-known members of the community; and the support of the broader community that has its roots and beliefs firmly anchored in its own Africanness through the expression of *Ubuntu*.

More importantly is the fact that the overall well-being of the children and the health of the project could not have been so well maintained were it not for the innovative, charismatic leadership of Mam Duma. She is driven by her passionate belief in the abilities of intellectually disabled children. This belief and ethos is the point of departure for the implementation of the project, the intentions to improve quality of life extend beyond intellectually disabled children to that of their families, and thus improved situations for disabled children in various villages as well as through affiliations have been made. Through its unique way of living, the project has been the catalyst from which the overall well-being and quality of life for its members and particularly those in the project have been improved.

However, having indicated the above success of the project, there is also the need to understand the continued challenges that confront the project in relation to the broader contexts within which the project finds itself.

The South African context regarding social services for disabled people and the related issues of poverty have to be taken into consideration as the backdrop against which this project has thus far struggled to obtain success. Providing adequate support for disabled people in the rural and more isolated areas has been problematic, and the poverty issue in these areas (as is the case of Mthatha) has contributed to the challenges faced by the government. Poverty therefore places a strain on the *Ubuntu* way of living, and continued poverty will result in less community support for the project. If follow-through from policy to planning and implementation continues to be slow, it will eventually have a negative impact on maintaining a good quality of life for disabled children within the project and the region as a whole.

Therefore, in the short term, *Ubuntu* will continue to play a prominent role in the development and sustainability of the project. However, there are long-term implications, especially in terms of financial sustainability. SANLAM as the primary donor for the physical structure of the project cannot continue to provide maintenance or upgrading costs for the structures. In the absence of adequate financial support, the project might find itself confronted with a dilemma. The struggle to maintain financial sustainability is one that will continue to plague the project unless a government partnership in the form of Social Development Services is implemented.

It is also clear that the current leadership plays an important role in the success of the project. However, Mam Duma is faced with personal challenges that impact negatively on her ability to maintain settings that are stimulating, dynamic, adaptive and supportive of community development in general and of disabled children in particular. However, it should be noted that the issue of succession to Mam Dumas's leadership has largely been ignored within the project and the community. In the long term this will become a particularly challenging issue for the ongoing lifespan of the project.

Despite these constraints, the project is indeed a means towards the much-needed eradication of poverty, not only amongst disabled communities, but also for communities as a whole. It is a project that needs the support of government, but that also serves as a lesson for those who are engaged with or wish to develop similar projects. The lessons to be learned are:

- Communicate and consult with all members of the project when you plan.
- Inform your members, be transparent.
- Be strategic in the implementation of your project and the way you involve people.
- Share knowledge and be prepared to plough back knowledge into the community.
- Motivate volunteers and show appreciation.
- Respect, understand and provide opportunities to people with intellectual disabilities.

Happy Home is clearly driven by the spirit of *Ubuntu* that is ingrained in the Africanness of the project. These are evident how the project is sustained, the level of community involvement, and its leadership in all spheres of governance. The project has demonstrated an ability to improve the life conditions of persons with intellectual disabilities. It has further demonstrated the substantial impact it has made at local and regional levels in the Eastern Cape. The ability of the project to harness financial sustainability through self-help initiatives is clearly demonstrated, albeit that the project is challenged by continued financial sustainability means. The current sustainability of the project is further demonstrated beyond financial means through their formation of parent structures within the broader communities and villages. It is this demonstration of diverse means of sustainability that makes this project successful and interesting.

3. WHIZZ KIDZ PROJECT

Description

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 youth with severe disabilities. The specific expertise lies in the provision of early intervention programmes to cognitively challenged cerebral palsied children; children with limited or no functional speech; autistic children and children with multiple disabilities.

The project has various activities to address the specific needs of the children. These include early and timeous intervention (children 0-3 years) and pre-school education (children aged 3-6years). Other programmes that benefit all the children including the older children consist of therapy; self-care skills and independence training; social and emotional development activities; activities to promote communication and language development; functional scholastic skills development; leisure and recreational skills development; life skills training; training and education activities for staff, parents and members of other community structures, as well as other extended services such as aftercare.

The project caters for 40 children of different racial groups and cultural backgrounds, and comprises 25 males and 15 females. The age range of the children is between 18 months and 15 years. Within a neighbouring suburb, the project has an extended unit that caters for the development of youth between the ages of 13 and 18 years. The programmes of this unit are focused on daily living activities. The unit is a recent and new development of the project.

Whizz Kidz takes its point of departure from the sentiment and belief that every single child, despite the disability experienced, can grow given the right stimulus and aides to enable growth. The objective of the project is to provide an effective educational programme geared towards the specific needs of each pupil 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 child and family life, and opportunities for future learning. The director who resigned her permanent post at a special school to assist severely and multiple disabled children who had been turned away by the formal educational system founded the project five years ago. The project started out with three children at hired facilities in a mainstream pre-school.

The project relocated in 2001 and is currently accommodated in a large single storey house. This renovated house accommodates the offices of the project, two classrooms for the younger children, an enrolment and assessment room, a galley style kitchen, and toilet facilities for the adults and children. The main classroom for the younger children is huge and allows ample space to accommodate the children with multiple disabilities. There is provision for physical activities at floor level. Additional outer buildings at the back section of the house accommodate the communications classes and the daily living activity classes for the young boys. Other outer buildings to be found on the premises include a shed/barn like structure. The playgrounds at the back section of the house are adorned with outdoor play and activities equipment. The grounds have well-laid out gardens at the front and back sections of the house. Although the inside of the main house and back access to the play areas do not adequately provide for wheelchair accessibility, the front entrance has been modified to facilitate this. The entire premises are fenced off and provide electronically controlled access onto the premises. The buildings and the property have been donated on an infinitive free lease basis.

The governance structure of the project consists of a board that provides advice and guidance to the director; a parent steering committee that assists with fundraising activities; and an administrative and financial component. The staff compliment consists of the director who has the multiple roles of teacher and principal, four teachers and three assistants. There is a small volunteer component to help feed and care for the children and to provide support to the teachers when required. Although the professional services located on the premises are private and separate from the project, they interact with the project through their provision of guidance and advice on the teaching programmes of the children. The project is registered as a section 21 company (semi-private/public company) and has recently affiliated itself to a service provider organisation in the disability sector.

Apart from the physical resources that the project has, it is well resourced for the implementation of its Augmentative Alternative Communications programmes. The project has a variety of specialised educational material and equipment. These resources are made available to and shared with other special needs facilities, professionals and parents who come into the project for training. The project is also well equipped with administrative resources.

The Ken McKenzie offshore trust which was established by the company's late chairperson and which is located in the United States of America assists the project with regular financial assistance. This foundation has also provided the physical structure to the project free of charge. Varied other donors and sponsors provide for and contribute towards the ongoing activities and

functions of the project. The ongoing renovations of the property are provided through the sponsorship obtained via the Forest Hill Company attached to the Ken McKenzie Foundation and other smaller community-based welfare organisations and businesses.

Other means of financial support are derived from fund raising events such as golf days, social events, and a specific appeals strategy in the form of Friends of Whizz Kidz that allow contributors the opportunity to make monthly contributions to the project. The monthly contributions range from R50 to R500 per pledge. Thus far the project has eight constant Friends of Whizz Kidz sponsors. Individual members of the community make personal donations to the project, between R50 and R5000 to further support the financial sustainability of the project. Participants in the programme pay monthly school fees of R660. Most of the immediate community members in close proximity to the project provide voluntary human resources for the daily upkeep of the project.

Although most of the project's networks are derived through contacts and close friends of the project director, they also have other networks, which have been built up during the establishment of the project. These are networks in Alternative Augmentative Communications; training entities; mainstream and special schools; and corporate and agricultural networks. The members of the board structure of the project (mainly corporate entities) as well as staff and family members participate in the project and share their networks.

The social structure of the project is embedded in a multi-cultural environment, in keeping with the diverse cultures represented in the project. Awareness of the diverse cultures is raised amongst the children by way of celebrating different cultural festivities and occasions.

Analysis

The success of this project has clearly contributed towards the unique educational approach and how the project has managed to remove some of the barriers to the development and growth of the children. Most significant is the improvement in the quality of life arenas of the children that deal with self-determination; emotional well being especially in the area of spirituality; physical and their material well-being. The development of individual programmes for the children is another factor that makes a tremendously positive contribution towards their self-esteem and their ability to progress despite the severity of their disabilities.

The successful use of AAC as an educative tool in the communication development of the children with limited or no functional speech, further contributes towards the success of the project as it has opened up opportunities to broaden and increase the project's AAC networks.

Separating the youth from the younger children at Whizz Kidz, and placing them at Teenwize, a separate unit of their own is another contributing factor to improve the lives of the youth. Their growth and personal development in terms of their sense of self and self-worth, their increased socialisation opportunities and communication abilities have greatly improved as a direct result of this separation.

The project's ability to remove communication barriers through the use of highly sophisticated equipment is attributed to the generosity of the community members and family members involved. They use their personal networks to acquire equipment and donate it to the project. The incorporation of various services offered by the project to the immediate community, has ensured the participation and commitment of community members. The creation of a one-stop service centre, such as providing administrative services, training services, therapy services, toy library services and leasing out of space to the community for social activities and events not only contributes towards the successful participation of the immediate community but also towards the sustainability of the project. At the same time the attitudes and mindset of the community is changed.

The highly skilled and committed staff is another contributing factor to the success of the project and their achievement of the improved quality of life of the participants. The intensive staff training, the encouragement, assistance and interaction with the children in all spheres of their development needs, impacted positively on the overall development of every individual child. Most interesting is how the project managed to challenge traditional gender roles within the care of disabled children, by appointing a man as a teacher assistant/carer.

In terms of ensuring its self-sustainability financially, the project has developed interesting fund raising activities that encourage the participation of the contributor. Underpinning the approach to the success of the project is the project director's leadership style and networking abilities. She has managed to engender growth and development through her ability to strategically select community members to participate on the project board structure. This has greatly contributed towards the acquisition of resources and the project's self-sustainability.

There is no doubt that the educational approach of the project has created much improvement in the lives of the children who participate in the project. This approach places the project in a good position to become a possible resource service centre to inclusive schools as indicated in government policy, *Education White Paper 6: Special Needs Education – Building an Inclusive Education and Training System* (Department of Education, 2001). The project has the necessary infrastructure to provide support in this regard, and at the same time would be in a position to stabilise their financial sustainability needs.

Although the project has obtained various successes in the development of the children, it is confronted by various challenges. In the sphere of financial sustainability, the lack of government funding forces the project to rely mostly on fund raising initiatives and being in the good grace of the immediate community and their international donor.

The fact that the project is still relatively young has not allowed it the scope to make a significant impact on the broader community. The project itself appears to be very isolated, especially since the children are not visible within the communities and within community activities. Other challenges include limitations in beneficiary intake because of school fees that are beyond the reach of the majority; poor awareness of the project's existence amongst health professionals; constraints in the ongoing development of the children; poor involvement of parents and families; and challenges pertaining to the succession of the leadership. One of the most important challenges that confront the development of the youths centres on issues relating to interpersonal relationships with family and friends and in matters of intimacy and issues of sexuality education. These are areas that are in need of far greater attention. Despite these challenges, the project offers important lessons to learn from for those who wish to start up or are engaged with similar projects. These are:

- Base planning and development on research before the implementation of the project.
- Ensure that there are well-trained, committed staff that have a love for children and that ongoing training is available to the staff.
- Ensure that the project has the necessary professional resources close at hand to assist with the various aspects of development.
- Diversity in expertise and the ability to bring diverse networks to the table are some of the components that should be inherent in governing structures.
- Versatile, dynamic and unstructured approaches to the development of children with multiple disabilities should be key.

- Have a positive attitude and mindset: ‘disability not inability’.
- Have faith in the integrity of community members.
- Ensure that all staff understand and implement key teaching strategies such as AAC and in building the independence of the children.

Whizz Kidz is a project that is truly driven by dynamic leadership style. The project is supported by the governance structures, strengthened by its vast networks and boosted by the services that it provides. The project, despite its relatively young age, has proven itself to be a very dynamic and interesting project entity for the development of children with severe disabilities. This is clearly demonstrated by how the project has managed the progression of the children’s potential, taking them through a steady progression from one level of development to the next. Although the project has demonstrated its ability for sustainability with mostly local resources, it has yet to demonstrate its ability to make an impact beyond the immediate community in which the project finds itself. The fact that the project does not receive funding from the provincial government raises concern. There is a great need for the project to ensure much firmer support in the form of government, to continue its services, as the project will not be able to sustain itself with the sole support from sponsors and donors. The project has the potential to progress from strength to strength.

C. COMPARATIVE ANALYSIS

1. INTRODUCTION

The projects in our study were selected first of all because they share characteristics of having a substantial impact on the quality of life of persons with intellectual disabilities, strategies to try and ensure sustainability, having a significant impact in the community and being innovative and interesting. Furthermore, to develop a representative picture of the processes and methods used in projects in South Africa to achieve improved life conditions for persons with disabilities, and to capture the complexities of demographic variability including rural vs urban areas. The three selected projects are located in three different provinces in South Africa namely KwaZulu-Natal (urban), the Eastern Cape (rural) and the Western Cape (urban).

In the analysis of the data the tight alignment between the processes and methods to improve the quality of life of the persons with disabilities and the specific context within which the project is being managed, became very clear and is illustrated in Table 3 which portrays the similarities and differences of the projects.

TABLE 3: SIMILARITIES AND DIFFERENCES WITHIN CASE STUDIES

Project Qualities	ASTRA	HAPPY HOMES	WHIZZ KIDZ
Location of Project	Western Cape-Cape Town-suburb	Eastern Cape-Mtata-Suburb	Kwazulu/Natal-Pinetown-suburb
Age of Project	54 years	8 years	5 years
Ethnicity	Jewish	Xhosa	Multi-racial –Zulu, Indian, Coloured, Afrikaner, English
Socio-economic status	Middle/working class-exclusive	Poor rural	Middle/working/poor mixture
Project Identity	Protective employment//small business/employment placement service provider	Self-help	Specialised education/intervention service provider
Service focus	Employment/placement and training	Parent and child development	Education and life skills development
Target Group	Intellectually disabled and psychiatrically ill adults and young people	Multi-disabled children and their parents	Intellectually and multi-disabled young children and youths
Government Registr./affill.	Non-profit organisation (NPO)/Cape Jewish Welfare Council/Western Cape Disability Network	Non-profit organisation (NPO)/Disabled Children Action Group (DICAG)-National Parent Organisation	Section 21 Company Registration/Association for the Physically Disabled - KZN
Implementation approaches	Medical and Social model approaches/therapeutic and employment	Social Human Rights approaches/poverty eradication	Medical and social model approaches/therapeutic interventions and educa-

			tion
Start-up involvement	Medical doctor in Psychiatry with support of rehabilitation group	Parents of disabled children	Education assessment specialist/professional-intellectual disabilities
Physical structure	Donated property/old house with recent extensions	Purchased small holding/old farmhouse/recent additions/renovations	Old house/donated infinitive free leasing/recent renovations
Governance structure and staffing	Executive Board Medical Board Staff component Volunteer component	Board of trustees Board of directors Parent executive Committee Volunteer staff component	Board of Directors Parent Committee Staff component Volunteer component
Cultural practices	Jewish Culture-Framed in spirit of brotherhood	Xhosa culture – framed in spirit of Ubuntu	No specific cultural practices-multi cultural project community
Outreach scope	Ad-hoc outreach to disadvantaged disabled people's groups	Affiliated village based parent structures	Outreach training programmes/surrounding areas
Networks	Jewish schools and homes for disabled Tertiary education institutions Jewish community welfare organisations Jewish religious networks Business communities Sheltered employment organisations International networks Board member networks	Community based organisations Business communities Private Health practitioners Veterinary Health practitioners Traditional Healers forums Traditional leaders forums Religious networks Local government networks Judicial systems networks Community members Board member networks Parent networks	Professional networks Mainstream and special school networks Tertiary education networks Local business and Corporate networks Board member and family networks Community members Parent networks International networks Training networks
Significant supporters	Cape Jewish Welfare Council Prominent individual Jewish community members and religious leaders Business communities International Jewish community	Insurance Brokerage company Prominent individual community members and structures Local business and retail community Parents	International Foundation Local welfare organisations Individual members of immediate community Local business communities
Government Participation	Small government subsidy provided Project participates in provincial department of Social development-	No government subsidy Project participates on ad-hoc basis in government consult-	No government subsidy Project participates within provincial educational structures on ad hoc basis

	employment issues	ing structures on social security health and education issues	
Disability knowledge/experience	Director previous knowledge and expertise in social development Staff and volunteers no prior knowledge of disability Governance structure expertise in mental disabilities and psychiatric illnesses	Project coordinator mother of disabled child Volunteer staff parents of disabled children Parent executive structure have knowledge and expertise	Director and staff knowledge of disability Some members of the governance structure have relatives with disabilities Parent committee have expertise
Funding supports	Jewish Welfare Organisations Government subsidy Community members/bequests/donations Local companies	Insurance company Local business/companies Local organisations Community members/donations	International donor Local welfare organisations Individual community members/bequests and community business entities.
Self sustainability practices	Membership fees Sales of products Interest of income Fundraising activities	School fees Membership fees Sales of farming produce and other income generating activities	School fees Fundraising events and activities Renting out of physical space Training activities
Major historical events	Through rehabilitation and training identified need for sheltered employment. Initially therapeutic, later developed into meaningful employment provision. Broadened services to job coaching and placement. Took on identity as Small Micro, Medium Enterprise (SMME) and worked towards employment equity. Developed with Jewish community support into multi-business and employment agency.	Political changes experienced in the country. Development of the South African Disability Rights Movement. Establishment of DICAG-national parent organisation. Activism for disability rights- mobilisation of parents. DICAG Mtata grants campaign-advocated right accessing social security/poverty eradication amongst disabled people. Parent mobilisation led to development of Happy Home.	Children with multiple disabilities rejected by formal special school system. Therapist started own project. Through personal networks managed to obtain funding for the project. Used AAC networks to develop educational programme. Broadened out programme to outreach training programme. Led to development of an “informal” one-stop service centre. Developed into specialised education and life skills training centre.
Favourable incidences/conditions	Transformation of project into business concept. Financing policy that engenders and supports transformation of protective or sheltered workshops/employment. Consistent Jewish welfare	Affiliated village based parent structures that build on sustainability. Part of the Disability Rights Movement. Involvement of a prominent commu-	Political and legislative changes in special education. Committed international donor. Opportunity to become a resource for full service schools as required by

	<p>support and Government subsidy. Have the capabilities to become resource entity for transformation of sheltered workshops.</p>	<p>nity member. Committed donor Progressive change of attitude towards disability. Political networks. Passionate parent/volunteer base.</p>	<p>education policy. Good committed networks</p>
Competing ideologies	<p>Expanding business opportunities Vs general well being of participants. Jewish exclusivity Vs government requirements to be all-inclusive. Therapeutic service provider Vs job coaching and employment provider/placement agency.</p>	<p>Opportunities in political affiliation Vs Apolitical identity of project. Intense support requirement in the establishment and development of the project Vs the intense support requirement for the development of village-based parent structures and projects. Identity of the project Vs DICAG Mtata identity. Project coordinators' leadership role within the project and DICAG Mtata Vs her personal obligations-succession.</p>	<p>Ownership/independence Vs community based ownership. Service provider Vs parent involvement. Establishment of project Vs outreach/expansion. Service provider identity Vs parent involvement and ownership.</p>
Important decisions/choices/connects.	<p>Although participants within the project strictly Jewish- the workforce is multicultural. Progressive move from purely therapeutic to that of meaningful employment and creating opportunities for employment placement through development of skills. Expansion of business and employment activities invited diverse support and interaction. Decided to introduce outreach programmes to disadvantaged disabled people's organisations.</p>	<p>Politically challenge the system. Separate and highlight disabled children's issues from disabled adults issues. Remain as close as possible to cultural/rural way of living within urban environment. Multi-pronged approached to poverty eradication and development. Prospects within the project changed Connections to prominent individual members within the community-changed prospects for the project.</p>	<p>Resigned a permanent position to establish and develop project. Relinquished traditional admissions criteria. Opening up of project facilities for financial gains. Bringing in additional services –creation of "informal service centre." Through personal networks and others brought important committed financial donors.</p>
Innovative and interest-	Target employment issues	Strategies used to	The strategic building of

ing	<p>as a means to add value to disabled people's lives/more emphasis on personal development. Progressive evolvement of sheltered workshop to business entity/changed perception of Astra's activities.</p> <p>The use of inter-dependence between participant, employee and project initiatives to enhance both the participant and the project.</p> <p>Culturally diverse workforce within a predominantly Jewish project.</p>	<p>overcome challenges Practice of Ubuntu principles as a means to survive.</p> <p>Their strive to continuously create an environment of equality for project participants (children) within the project.</p> <p>The impact it has made on the broader community and remote villages.</p> <p>The impact of self-help activities within the project on the youths and the contribution it makes towards poverty eradication.</p> <p>Specific leadership style of the coordinator.</p>	<p>networks to harness resources for the project.</p> <p>The manner of acquiring sophisticated communication tools/equipment for the AAC programme through networks.</p> <p>Challenged the traditional role of men in caring of disabled children-included a man in the staff component.</p> <p>The separation of the youths from the younger children.</p> <p>The use and application of the skills, resources and equipment to create an informal one-stop service centre.</p> <p>The dynamic leadership style of the project leader.</p>
Challenges	<p>Finding a balance between the interests of the participants and the project.</p> <p>Tensions between government policy requirements and the projects exclusivity.</p> <p>Maintaining a conducive environment within the project to prevent the disintegration of the supportive net created through inter-dependence.</p> <p>Ensuring the financial support base of the project.</p> <p>Outreach opportunities limited by human resources capacity.</p> <p>Obtaining the buy –in from the department of social development as transformation consultants</p>	<p>Continued poverty. Funding limitations-insufficient donor or sponsor support.</p> <p>Slow implementation of Government services.</p> <p>Ubuntu practices threatened by continued poverty within the region.</p> <p>Leadership succession</p> <p>Providing ongoing support to rural affiliated parent structures.</p>	<p>Financial sustainability. Limitations in participant intake.</p> <p>Poor awareness of the project's existence within community.</p> <p>Poor awareness of project's services amongst health officials.</p> <p>Poor involvement of parents and family – political and child development areas.</p> <p>Poor child and staff ratio.</p> <p>Succession of leadership.</p>

2. Conclusions based on the South African case studies: themes and important factors that contributed to change and success

Table 3, over and above the indication of similarities and differences, provides a rich insight into the project life of these three case studies. It is clear that in all three projects, their humble beginnings were placed on a platform of need. For Astra it was the fulfilment of employment opportunities, while Happy Home and Whizz Kidz felt strongly that they wanted to fulfil a need that is far more human rights based with a specific focus on social inclusion. For instance, this could be the need for access services, such as social security, social developmental services and education. Noticeably, a key factor in the implementation of these last two projects was the political transformation of the country from Apartheid to democracy and the manner in which this influenced the projects' developments, and more specifically towards disability and the need for the development of disabled people within a social human rights developmental context. This is clearly indicated through Happy Home's implementation that rested primarily on a base of activism, while Whizz Kidz's implementation rested on the right to equality and universal access. Political influences also played a key role in the gradual shift of attitudes and approaches to disability within the Astra project. Progressively with time, this project adopted a more social model approach towards disability, albeit the fact that they are trying to balance their efforts with the specific medical needs of their participants. Despite these differences in their approaches to disability, each of these projects has a unique identity that is shaped by the manner of implementation, which ultimately led to the success of the projects. For instance, Astra's identity has been progressively shaped over time by the creation of interdependence between the various aspects of the project. Happy Home has taken on the identity of *Ubuntu* that is in keeping with their cultural context, whilst Whizz Kidz's identity rests on the dynamic leadership that is to be found within this project. What connects these three identities to each other are the overlapping factors in their attainment of success, which brought about a level of commonality.

One of the key factors in the development of people with disabilities that were of common interest relates to the manner in which interaction happens with disabled people. In all three case studies the key factor for success was the need for positive attitudes and mindsets with a focus on the person's ability and not the disability. More importantly, was the need for commitment from those who worked with disabled people and their ability to relate to disabled people with the required respect, understanding and love of children especially. The results of these approaches were evident in the changes that occurred within the participants of these projects, and the level of confidence that they have progressively acquired over the years through their participation and involvement in these projects.

Over and above the manner of interaction, was the identification for the creation of positive environments, the importance of skills development and the creation of opportunities to engender development and growth of disabled people. The results of the creation of such an environment is evident in the way the participants of Astra positively took to the progressive and dynamic development of the project, the way in which the youth of Happy Home acquired business skills and conducted themselves with confidence in their income generating activities, and the manner in which the children at Whizz Kids progressively developed and acquired communication and social skills.

How the workforce or volunteers interacted and related to the participants within these projects is an equally important factor in the development of the project and the participants. In all three case studies, the important factor for maintaining a good and committed work force was the need to show appreciation, motivate workers and engage in constant communication and consultation and above all apply the principles of transparency. This is evident in the way the workers applied themselves to, and interacted with participants to instil skills. The provision of ongoing training to develop the skills of the workforce was just as important, as it was to develop the skills of the participants. It is interesting to note the indication in all three case studies that the application of versatile, dynamic and unstructured approaches to the development of the participants proved to be a key factor that contributed to their successful development and the changes that occurred within the projects.

As indicated above, it was evident that the success of the project's positioning and existence within the community was an equally important factor in the ongoing development and sustainability of these projects. The importance of developing creative ways to raise awareness of their projects and disability issues contributed towards harnessing the involvement of the community in these projects. The positive manner in which all three case studies derived involvement from their respective communities attest to their success in the application of this approach. All three projects displayed great faith in the integrity of the community, which was demonstrated by the manner in which they shared and ploughed back their knowledge of disability issues into the community. In doing so, they derived great support, built and strengthened community relationships, and improved the way the community in general responded to people with disabilities.

In all three case studies, it was also revealed that the manner in which the development of the project occurs, and how it is governed are important factors for success that need to be considered, especially for the ongoing sustainability of the project. Important contributing factors for the attainment of success are those of building reliable and trusting networks, to have profession-

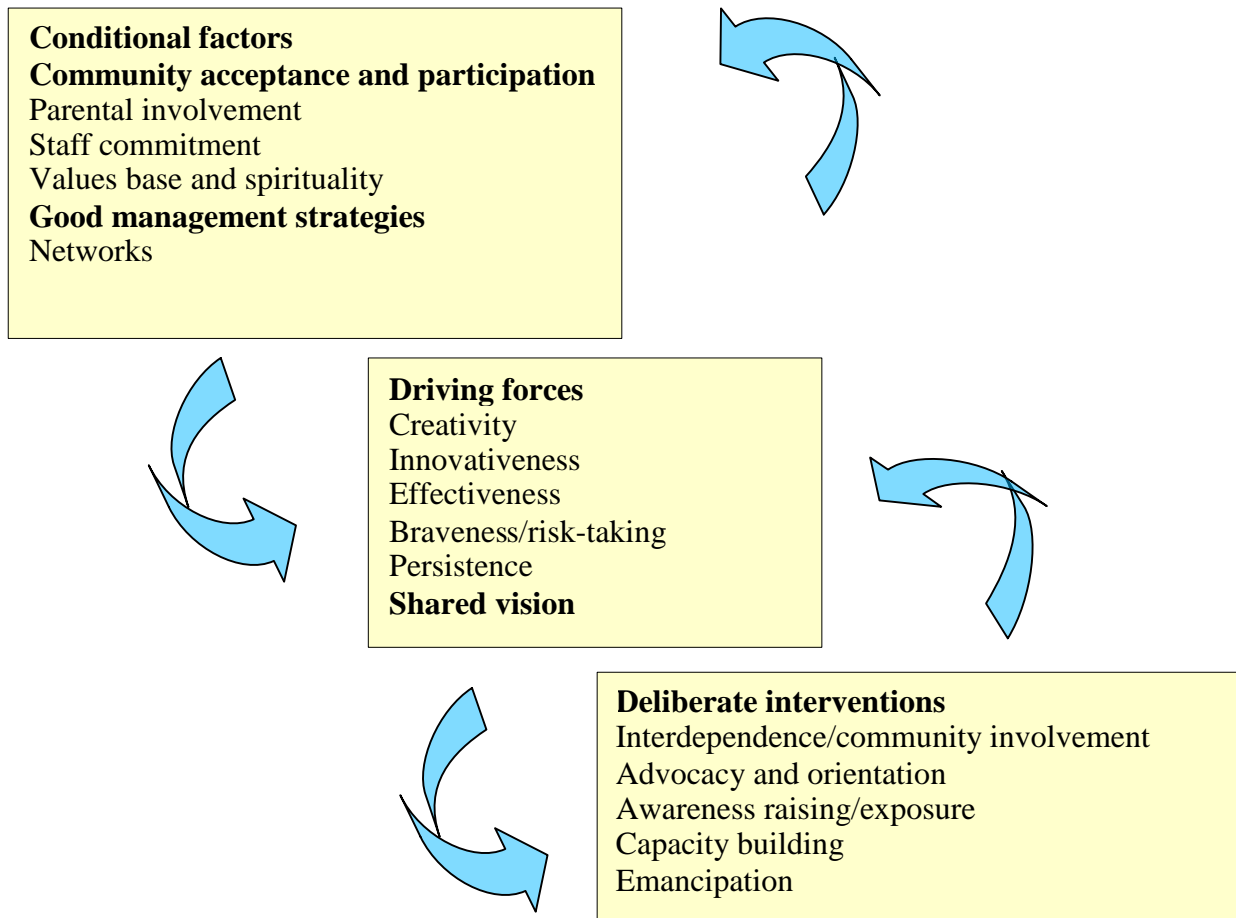
alism and diversity of skills inherent within the governing structure, be strategic in the planning and development of the project, and most importantly, to have information on hand so as to be informed on matters relating to government policy and legislative developments, for example. These factors were evident, especially in how their governance structures were set-up, the manner in which strategies were applied to build and obtain networks, the dynamic leadership within the projects and the measure of information that each project possessed which was considerably broader than the political sphere. The element of building a vast and diverse network as a strategy for project development comes through as one of the important factors in the ongoing development and sustainability of the projects. At the same time this is a specific factor that strongly binds commonality amongst these three projects. However, the overall key element to a good start in the successful implementation and development of projects appears to be that of research and planning prior to implementation.

In all three case studies, specific contexts and conditions experienced acted as the driving forces for implementation, that nevertheless served as catalyses for deliberate interventions in the improvement of quality of life of the participants within these projects.

3. Discussion of South African findings in relation to preliminary overall categories

At the consultative meeting in Stockholm in 2005, commonalities regarding the factors that contribute to success in terms of improved QOL of persons with intellectual disabilities in the various projects were identified and discussed. It was concluded that commonalities could be divided into three main categories with specific themes that related to specific individual countries' projects. It can be illustrated as follow (with specific themes as it relates to the South African data analysis added in bold).

FIGURE 1: SUB-CATEGORIES AND THEMES



As mentioned in the introduction to this section, the specific context within which the projects are being managed is very clear (as illustrated in Table 3), making the discussion of similarities and differences in the identified categories and themes a complex process. While all three projects strive to improve the quality of life of the persons with intellectual disabilities in the projects, the manner in which they strive to achieve these outcomes are different because of the diversity of cultural and individual values as well as the needs and experiences of the communities they serve. The QOL of the persons with disabilities in the projects is therefore influenced by the individual contextual characteristics of the specific project which reflect the personally relevant values and experiences unique to the individuals involved in the project, the basic needs of the communities they serve as well as the cultural experiences and meanings that specific groups of people share.

The interaction between these influences and the contextual dependency of the projects must be acknowledged in any discussion of the identified categories, namely, conditional factors, driving forces and deliberate interventions.

Conditional factors

In all three projects specific conditional factors play a major role in the determination of success. Community acceptance, parental involvement, staff commitment, a solid values base and spirituality, good management strategies and the establishment of suitable networks contribute to success but differ qualitatively when the personally relevant values and experiences of individuals, the basic needs of the community and cultural experiences and meanings are taken into account. This can be illustrated by the contrast between the contextual background of the Happy Home and Astra projects.

Happy Home: As discussed in the case study, the values base and spirituality within this Xhosa-speaking community is based on a strong sense of community, the willingness to serve not only of local inhabitants but also of the wider Xhosa-speaking community. In the spirit of *Ubuntu* community involvement and acceptance is described by the project leader as ‘sharing’ and ‘acceptance’ and evokes emotions of collectivity and of collective co-operation for collective survival in a poverty stricken rural community. This strong sense of community ensures community acceptance, staff commitment, good management strategies and the establishment of suitable networks as well as the empowerment of parents and their children.

Astra: As discussed in the case study the Astra project also represents a close-knit community where the development of a specific community within a large cosmopolitan and culturally diverse city, is seen as a priority. This commitment creates positive conditional factors that impact positively on the QOL of the persons with disabilities and ensures community acceptance, good management strategies and the establishment of suitable networks.

Whizz Kidz: In contrast with the other two projects community acceptance and parental participation is still in an early stage despite the fact that the project caters for a group of children from diverse cultural backgrounds. Whizz Kidz does not serve such a definitely defined community as the other two projects with the result that the personally relevant values and experiences of parents and members of the wider community have yet to be explored in greater depth to achieve wider community acceptance and involvement. On the other hand, the positive values of management and staff ensure the commitment of all involved and create positive conditional factors.

Our data analysis indicates that in all the projects the creation of conditional factors can be directly tied to the quality of leadership in each project.

Driving forces

The driving forces in every project relate to creativity, innovativeness, effectiveness, braveness/ risk-taking and persistence as well as a *shared vision*. Our data analysis indicates consistently that the driving forces behind every project are directly related to the leadership roles of either an individual (Whizz Kidz and Happy Home) or a group of individuals (Astra, although an individual led the process initially) who have a clear vision of what the desired state of affairs for a specific group of people within a specific context should be. The literature (e.g. Swart and Pettipher, 2001) indicates that a vision only becomes shared once it unites with the personal visions of all the people directly involved in a specific project and community context. A shared vision incorporates all role-players' values and experiences and becomes part of creating and implementing a new system. In the case of Happy Home, Whizz Kidz and Astra the creation of a shared vision within the project has been the major driving force behind the creativity, innovativeness and effectiveness of the projects. In the case of Happy Home and Astra a shared vision within the specific communities they serve has also been achieved. As discussed in the section on conditional factors, data analysis once again indicates leadership as a transcending agency.

Deliberate interventions

Deliberate interventions in the South African projects relate directly to conditional factors and driving forces. Community acceptance, parental and staff involvement for example influence the success of interventions that focus on awareness raising, advocacy campaigns and the development of capacity building amongst participants as well as communities and the emancipation and empowerment of people with disabilities. Once again these interactions are influenced by the individual contextual characteristics of the specific community the project is located in. The fact that the Astra project for example functions in a relatively affluent urban area ensures the success of the Coffee Time coffee shop/small restaurant and the Gifttime project. These interventions contribute to awareness raising, capacity building of participants and the emancipation of people with disabilities. This is a project that cannot be replicated in the Happy Home context, but once again creative leadership has initiated specific interventions in the Happy Home project where these interventions contribute to the empowerment of participants (e.g. farming activities and the selling of farm produce to supermarkets). Outreach projects also include development and empowerment programmes within the wider communities. In the case of Whizz Kidz, the various well-planned interventions contribute to advocacy, capacity building and emancipation.

The leadership qualities at management level and the determination to actualise a shared vision contribute to the success of deliberate interventions.

4. Conclusion

The overarching aim of the South African study, as part of the larger international study has been to explore, understand and describe successful change processes and learn from them. The conclusions to the specific research questions will now be discussed briefly:

- Which projects resulting in sustainable improvements of life conditions for adults and children with intellectual disabilities can be found in the four countries?
- Which are the most strategic change agents, internationally, nationally and locally?
- Which methods are most effective in order to initiate and maintain processes of change?
- What other factors, deliberate project interventions as well as contextual factors, are important to achieve a positive change?

Three projects from diverse geographic, cultural and socio-economic backgrounds have been identified as most successful in developing sustainable improvements of life conditions for adults and children with intellectual disabilities in South Africa. The three projects are Whizz Kidz, Happy Home and Astra.

After a rigorous process of literature review, data generating activities including interviews and site visits and data analyses, the **most strategic change agent** within the South African context has been identified as that of *leadership*. It is concluded that a leadership style that is dynamic and sensitive to the unique contextual characteristics of specific communities, reflect relevant personal values and understand the basic needs of a specific community, facilitates the development of a shared vision and resultant commitment to the development of sustainable projects.

Methods that are the most effective in initiating and maintaining processes of change first of all reflect a commitment to a social model of disability against the background of the South African Constitution. Effective methods furthermore are sensitive to contextual factors, including socio-economic factors and therefore will differ from community to community. It is however clear that all three projects have specific generic methods in common e.g. advocacy and public awareness campaigns, creation of independency and empowerment with the help of job creation opportunities, outreach development programmes and skills training opportunities. The finer details of generic methods differ however from context to context.

It cannot be stressed enough that acknowledgements of culturally specific, individual and common values are essential to achieve positive change. The three South African projects are examples of projects where the interaction of these factors and their context dependency play a major role in the success of deliberate project interventions. Furthermore, the emphasis on interventions should not lose sight of the people it is intended for as quality of life is a matter of subjective experience and the concept has no meaning apart from what a person feels and how they experience their lives themselves (Taylor and Bogdan in Hensel, 2001).

The question we need to ask ourselves in our conclusion to our discussion is whether we have really listened to the voices of the persons with disabilities in our assessment of the success of the projects they are involved in.

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Annexure 1
South African QoL

**MEASUREMENT OF IMPACT OF OOL ON PERSONS WITH DISABILITIES
WITHIN SOUTH AFRICAN CONTEXT**

Domain and specific criteria	Exemplified by/ characterized by individuals who	Effective programme approaches will for example
1. Self determination		
<u>Criteria 1:</u> Choice-making	Can communicate a preference or identify a preference	Incorporate individual choice in any given activity Have clear communication with individuals concerning areas of possible choice and the limits within which choices can be made Increase the number of choices related to a given activity Raise the significance in terms of risk and long-term consequences of choices made
<u>Criteria 2:</u> Self management	Use self-observation during which individual discriminates and records that a given target behaviour has occurred Use self-instruction strategies to provide own verbal prompts for solving a problem	Provide instruction in appropriate self-management strategies to enable individuals to track and evaluate their progress on various activities, including goals and objectives. Included in the above will be self-management of emotions and behaviour.
<u>Criteria 3:</u> Decision-making	Make a decision by being able to identify alternatives as well as consequences of actions.	Incorporate opportunities where individuals learn how to define the issue or problem about which a specific decision is to be made, how to collect information about specific situations and how to use this information Provide participatory decision making opportunities where individuals can identify and evaluate consequences and outcomes of actions based on various options
<u>Criteria 4:</u> Personal goal setting	Become the causal agent in his or her life by applying the skills necessary to plan, set and achieve goals	Promote goal setting by identifying specific goals, developing objectives and tasks to achieve these goals and evaluating desired outcomes Provide the means, opportunities and mechanisms that can support the realization of individuals personal goals

<u>Criteria 5:</u> Personal control	Believe that individual has control over outcomes that are important to her/his life Know how to communicate their needs and wants appropriately	Advance attitudes that enable individuals to act in a psychologically empowered or self-realizing manner Provide opportunities where internal perceptions of control as well as positive self-awareness are positively advanced including communication skills in order to communicate personal needs and wants
2. Interpersonal relations		
<u>Criteria 1:</u> Relationships with family and friends	Have friendships with people other than family and support staff	Allow individuals to see family and friends when they want Involve families in provider-level decision-making Actively advance opportunities for individuals to form friendships Use positive behavioural approaches that focus on the development of appropriate social skills
<u>Criteria 2:</u> Intimacy	Have a positive sense of the self and body and value and appreciate own sexuality Experience own sexuality	Implement strategies to enable individuals to develop necessary life skills and protection measures necessary for the development of their sense of self-worth, positive identity and healthy sexual development
3. Social inclusion		
<u>Criteria 1:</u> Community involvement	Participate in everyday integrated activities in their own communities and are not segregated on the basis of disability from persons who do not have a disability	Provide the necessary opportunities for community integration and participation Actively develop and promote normalized and inclusive environments
<u>Criteria 2:</u> Supports	Have access to an inclusive and integrated support network	Interface with other support networks in community
<u>Criteria 3:</u> Employment and work environment	Pursue a meaningful career in the local community and are not limited to participating in jobs that are exclusively for persons with disabilities	Facilitate and maintain community integrated employment
4. Rights		
<u>Criteria 1:</u> Dignity	Have a positive sense of self and dignity, believe him/herself to be significant because they are treated with respect	Actively encourage positive sense of self by respecting and protecting individuals with disabilities
<u>Criteria 2:</u> Equality	Experience the same support as others in the community Have equal opportunities as non disabled peers and experience equity amongst disabled peers	Speaks/organize and participate in advocacy campaigns to combat discriminatory attitudes in community Actively raise awareness on legislation that encourages equality e.g. Employment Equity Act

<p><u>Criteria 3:</u> Access</p>	<p>Have access to meaningful learning, employment as well as recreation and leisure activities</p> <p>Have physical access to classrooms, bathrooms, transportation etc.</p> <p>Have access to appropriate public-funded support services</p> <p>Have appropriate access to information</p>	<p>Provide opportunities to access various activities and actively advocate that access on emotional and physical levels is a right and not a privilege</p> <p>Advocate for and actively develop barrier free environments that are readily available to individuals</p> <p>See to it that individuals have access to all the public-funded support services they need</p> <p>Information is presented in a manner that gives opportunity for understanding and absorption.</p>
<p><u>Criteria 4:</u> Privacy</p>	<p>Have a satisfactory amount of privacy</p>	<p>Respect the privacy of individuals and see to it that ample time for privacy is provided, that a place to keep own things is provided for, and has created a place and space to be alone at times.</p>
<p>5. Emotional well-being</p>		
<p><u>Criteria 1:</u> Self-concept</p>	<p>Have a positive self-concept and self-identity</p>	<p>Encourage the development of a positive self-concept by providing positive feedback on all system levels</p> <p>Encourage opportunities for the development of self-awareness and general competencies and feelings of confidence</p>
<p><u>Criteria 2:</u> Spirituality</p>	<p>Have a personal belief and value system that include an understanding of the meaning and celebration of life</p> <p>Have the opportunities to experience life through nature, music or art and to celebrate special life events that are meaningful in own culture group</p>	<p>Provide opportunities for the development of personal value and belief systems</p> <p>Provide opportunities for the development of spiritual well-being and respect individual cultural beliefs and values</p>
<p><u>Criteria 3:</u> Stable, safe and predictable environment</p>	<p>Live in an environment that is safe, predictable and stable and are satisfied that basic needs are met and that opportunities to development and learn are provided</p>	<p>Provide an environment where basic needs (food, shelter, safety, meaningful social contact) are met and provide a range of opportunities for personal growth and development</p>
<p>6. Personal development</p>		
<p><u>Criteria 1:</u> Education</p>	<p>Participate within educative activities or experiences educational activities aimed at developing skills that are needed to participate in an integrated society</p> <p>Experience education within a progressive manner and displays a clear indication of development of abilities</p>	<p>Has provided opportunities and activities that promotes the maintenance or improvement of knowledge and skills in a manner that enhances and gives opportunity for the expression of abilities and that promotes personal advancement and independence</p>

<p><u>Criteria 2:</u> Creativity</p>	<p>Ability to pursue activities that gives expression to creativity in forms of personal choice such as for example singing, dancing, art work or mastering the art of engaging within a creative activity that brings about personal growth</p>	<p>Provides opportunities for creative expressions within a manner that is fun and spontaneous to encourage abilities for skills development and self expression that would bring about personal growth and development</p> <p>Has opportunities for creative pursuits that encourages social inclusion</p>
<p><u>Criteria 3:</u> Purposeful activities</p>	<p>Engage within activities that are important to the self and that brings about and enhances self worth</p> <p>Engage in activities that contributes to the well being of the household and of the community e.g. household chores</p>	<p>Provide opportunities for purposeful activities as a means to support and monitor growth in terms of self development</p>
<p><u>Criteria 4:</u> Fulfilment</p>	<p>Has realized aspirations or has achieved personal goals or engaged within activities or expressed a sense of being, belonging and becoming that indicates sustained satisfaction, fulfilment and advancement</p>	<p>Incorporate opportunities or activities that enables the achievement of self fulfilment through the creation of an environment that provides for basic needs to be met, and that provides a range of opportunities within the individual's potential for self advancement</p> <p>Provides activities or tasks that are achievable and contributes to feelings of mastery and fulfilment</p> <p>Provides opportunities for personal choice and control</p>
<p>7. Physical well-being</p>		
<p><u>Criteria 1:</u> Physical health maintenance</p>	<p>Has the ability to engage in personal hygiene, can attend to personal grooming with minimal support or are able to express or communicate any need for assistance in maintaining a good healthy physical appearance</p> <p>Participates in or doing activities of daily living that promotes physical well-being</p> <p>Express the ability to see to personal health or social needs</p>	<p>Provide for or ensure good nutrition intake</p> <p>Creates activities that promotes, encourages or engages individuals in exercise</p> <p>Has activities that encourages and engages individuals in amongst others personal hygiene, care and grooming</p> <p>Provides the necessary supportive mechanisms and programmes for good physical and psychological health maintenance and ill health prevention</p>

<u>Criteria 2:</u> Physical belonging to ones environment	Expresses a sense of physical belonging within the individual's arena's of inter-action such as the home, work place, school, neighbourhood or community	Have created a welcoming environment that gives and supports the sense of belonging Ensures and encourages participation in activities within all spheres of daily life activities- within and outside of the project or program environment to instil a sense of physical belonging
8. Material well-being		
<u>Criteria 1:</u> Ownership	Has managed to acquire personal possessions of choice	Encourage and support the acquisitions of personal possessions Belongings are kept secure Creates and encourages an environment of personal choice and self control in the acquisition of personal possessions
<u>Criteria 2:</u> Financial income and stability	Has managed to secure financial income either through employment or receives social security such as disability or Care Dependency Grant	Have mechanisms in place to develop potential for employment through skills development Assist and supports the placement for employment in a manner that optimizes effectiveness and productivity of the individual Supports and assist the obtainment of social security
<u>Criteria 3:</u> Shelter	Expresses and feels secure in the knowledge that they are sheltered in a secure and safe environment and which they can refer to in a manner that expresses belonging or ownership such as individual homes, community homes or centres	Encourage the right to or the acquisition of a safe and decent shelter Incorporate activities and programmes that develop and engenders skills for independent living in shelters of choice
<u>Criteria 4:</u> Social economic status	Has managed to generate income through a range of activities as a means to contribute to or improve the overall social economic status of self	Create opportunities for and develop individual skills and potential to assist in the development of and enhancement of individual economic status
9. Ubuntu		
How we live with and amongst others in the home and community		
<u>Criteria 1</u> Collectivity	Experience group solidarity and collective unity within the home and wider community	Actively develop and encourage the cardinal believe that a person can only be a person through others

<p><u>Criteria 2</u> Interdependence</p>	<p>Experience supportive mechanisms and mutuality within the home and within the broader community</p>	<p>Engenders the abilities and consciousness to share, help and provide peer support to others in need and to ask for help and assistance in turn as a means to ward of poverty and deprivation</p>
<p><u>Criteria 3:</u> Rights and responsibility</p>	<p>Experiences individual rights and express responsibility towards that rights</p> <p>Have recognition and respect for the rights of others</p>	<p>Through awareness bring about an understanding of individual rights and responsibility, develop the necessary skills to engage with the expression of individual rights and responsibility</p> <p>Bring about awareness of the need to respect the rights of others</p>
<p><u>Criteria 4:</u> Participation</p>	<p>Feels welcomed to participate and contribute to activities within the home and broader community</p> <p>Experiences a sense of acknowledgement as a member of the home and broader community through individual and collective contributions</p>	<p>Advance positive attitudes within the family and community that encourages full participation of individuals in family and community activities i.e. cultural and other activities</p> <p>Encourage the belief of self and others that individuals with intellectual disabilities has a contribution to make within the home and broader community</p>