



CONFERENCE
Strategies to Overcome Poverty & Inequality
"Towards Carnegie III"
University of Cape Town, 3 - 7 September 2012



This paper was presented at "Towards Carnegie III", a conference held at the University of Cape Town from 3 to 7 September 2012.

Please note that copyright is held by the author/s of the paper, and it may not be reproduced or transmitted in any form or by any means, electronic or mechanical, including photocopying, recording, or by any information retrieval systems, without express permission from the paper's author/s.

Theme: Other – Capacitating for change

Youth and disability-inclusive development: collective agency and reciprocal capacity development

Theresa Lorenzo, Disability Studies Programme, Department of Health and Rehabilitation Sciences, Faculty of Health Sciences

Abstract

Disability-inclusive development advocates for equal opportunities for disabled people in all aspects of economic, political, social and cultural life. This paper draws on two studies – the author’s PhD on how disabled women equalise opportunities for social and economic development (Lorenzo, 2005) and a national survey on youths’ strategies for sustaining their livelihoods (Lorenzo and Cramm, 2012). Both studies found that the needs and aspirations of disabled youth and women are similar to their non-disabled peers. The barriers to participation in education and employment are related to family support and access to financial resources and information about opportunities and resource rather than to the person’s impairment.

Both studies were collaborative projects between disabled people’s organisations (DPOs), community based non government organisations (NGOs), postgraduate students and staff from occupational therapy departments at higher education institutions. The participatory research approach has provided regular spaces to engage in reciprocal capacity development to explore strategies to implementing disability-inclusive policies.

A network of action spaces and capacitating community based workers to engage the agency of youth and women collectively to become productive citizens involved in reciprocal learning by local community structures, service providers and higher education institutions in creating disability-inclusive public services.

In addition, the implications include curricula changes to become more inclusive of disability issues in disciplines across all faculties at higher education institutions, so as to prepare future policy makers, business community and public service providers for this task, will be shared.

Introduction

This paper looks at who was involved? What was done? What works and why? How we conceptualised strategies and recommendations for up-scaling disability inclusive development for youth to address poverty and inequalities experienced by disabled youth.

Who is involved

The first study with disabled women in informal settlements began in 1998 and involved three staff members in the occupational therapy department at University of Cape Town (UCT), together with two NGOs, namely the community rehabilitation workers (CRWs) of the South African Christian Leadership Assembly (SACLA) Health Project, and Disabled People South Africa (DPSA).

DPSA was formed in 1984 in response to the discrimination that disabled people experienced, especially black disabled people. They mobilised and organised as a 'resistance group' against oppression on the basis of race and disability. Their main focus of activity was on political education, particularly in the deep rural areas and townships of the country. The organisation plays a critical role in advocating for the integration of disability issues in the policy development processes. As the leading national cross-disability political organisation in South Africa, DPSA has become a powerful mechanism for ensuring the achievement of human rights and development of disabled people. There are nine provincial structures, with the Disabled Children's Action Group (DiCAG) recognised as a sister organisation that lobbies for the rights of disabled children through their parents. DPSA was a strategic partner in the research, firstly, because the question was raised by the chairperson of the Disabled Women's Development Programme (DWDP), and secondly, and their Disability Economic Empowerment Programme sought to address poverty alleviation and economic empowerment of its members.

SACLA Health Project is a grassroots, primary health care, non-government organisation (NGO) operating in various informal settlements in the Khayelitsha and Nyanga districts. It was established in the 1980s to provide accessible primary health care services to the poor. The late Dr Ivan Toms was the founder and director. The project trained local community members as community health workers. In 1987, Marion Loveday, a physiotherapist, initiated the training of community rehabilitation workers (CRWs) in response to needs identified by the community. The community of mothers of disabled children and disabled people elected a mother to be trained to work in the area where she lived. The focus of activities expanded from home visits and referrals to include setting up day care centres for disabled children, income generation groups for disabled adults, and disability

advocacy and awareness campaigns. Thus there was growing acknowledgement of equal opportunities and social integration, as essential components of community-based disability inclusive programmes (Hermanus, 2000; Lorenzo and Saunders, 1999; Loveday, 1991).

DYESL study

Since 2007, a collaborative study was initiated by the Disability Studies Programme in Department of Health and Rehabilitation Sciences at UCT with occupational therapy departments at five other universities in South Africa, postgraduate students, community based workers in health services, NGOs and DPOs. The study has explored the strategies disabled youth use for sustaining their livelihoods followed by a survey of disabled and non-disabled youth to identify inequalities.

What is being done

Targeting barriers to participation and inclusion to address poverty alleviation and inequality has been the focus of the two community based research collaborations.

In October 1996, the **Masiphatisane¹ Disability Forum** was constituted to address the need for better co-ordination of services and strengthen support systems through the participation and self-representation of disabled people in decision-making processes in Khayelitsha and Nyanga districts. The Forum met every second month to look at issues of disability related to service delivery, public awareness and advocacy, skills development and accessing resources (Saunders, 1998). Through a prolonged process of engagement, the three partners decided to initiate a collaborative study to explore the experiences of disabled women in poverty and development initiatives.

Some of the women who participated in the research were also members of the **Community Disability Entrepreneurship Programme** which had humble beginnings. The first steps towards facilitating income generation for disabled adults known to SACLA were taken in 1992 with support from CRWs and an occupational therapist at the time. Two groups of disabled people in Site B and Site C in Khayelitsha received training and seed money to start a leatherwork project and a sewing project. Developments were hampered by political violence in the run up to the first democratic elections of 1994. Community development training in 1995 helped to identify the number of skills for income generation that the CRWs had amongst themselves. Over a period of eighteen months,

¹ *Matiphatisane*: Xhosa meaning ‘holding together’ reveals the spirit of co-operation in a group. The initial workshops were coordinated by the SACLA Health Project to facilitate NGOs working in disability to begin working collaboratively with

three groups were formed in collaboration with the Occupational Therapy Division at the University of Cape Town (Van Niekerk, Mdlokolo and Lorenzo, 2006; Lorenzo, Van Niekerk and Mdlokolo, 2007) as a research and development initiative. SACLA provided a home base for the study, and played an important role in service delivery. The provincial co-ordinator of the Disability Economic Empowerment Programme of DPSA was a co-researcher. The research process provided fertile ground for understanding the factors that influenced opportunities for human development and policy implementation.

Narrative action-reflection (NAR) workshops is a method for generating data collectively in participatory research, as well as a strategy to equalise opportunities for disabled people in development. The workshops involve a combination of action-learning and storytelling to describe the meaning of human actions linked to larger social concerns (Lorenzo, 2005; 2010). We organised workshops monthly for a whole day. Disabled women identified their deprivations and potentials which were categorised into five areas (see table 1). The workshops illuminated the complexity of disability and poverty as the women engaged in the creation of a network of action spaces. A collective approach to disability recognises the interdependency of people, which enables the inclusion of disabled women in mainstream development initiatives (See Figure 13). Bulelwa’s story illustrates these aspects:

Table 1: Human poverties and potentialities

Aspect	Deprivation	Potentiality
1. Self-identity:	loss	agency
2. Family life:	pain	pride
3. Sustaining a livelihood:	missed opportunities	being providers
4. Health and social services:	ignorance	CRWs as a buffer
5. Accessing resources:	marginalised	being free

A better life together

Bulelwa became the ‘disability evangelist’ in the study. She was a vibrant entrepreneur, very hard-working while at the same time as being very concerned for the well-being and growth of the women. It was significant that the women began to recognise changes in each other over a period of time. Bulelwa grew in confidence to speak about disability to other women as well as the wider community organisations. It inspired her self-development. She mobilised the women to re-think their images of disability and challenge public stereotypes. They acted collectively to raise awareness and advocate for change in attitudes towards disability.

After the first workshop where I told my story, I felt much stronger. I realised these workshops could really help other women in the same situation as me. Our rehabilitation did not help us return and settle back with our families or communities. Here I made a clay sculpture of a plate and two women to share how I changed from gaining knowledge of disability rights and advocacy skills. The workshops helped us to find knowledge and information for each other. We felt happier. We recognised the gains we've made in changing our living conditions. These skills have led to a better life together. I made myself using clay. I want to show you that before I became disabled, my body was thin. I was small before and you can now see how big I am. So I want to share the good news so that others can be big like me. I must be the light, even in the community and preach about disability and how they can treat disabled people. I talk about disability. I became more confident and gained skills in being able to change things. I was used to speaking in church and sharing my testimony. Now I speak about disability. I also loved to sing and dance... So I was not the only one who wanted to shine as a light to change attitudes to disability in ourselves, amongst our families and our neighbours. The workshops also helped us see how we could heal each other. The workshops gave us courage to be visible in our families and community again.

Bulelwa's story illustrates three ways in which the disabled women contributed to rebuilding a **collective identity** and **collective agency** occurred at an individual, family and community level and involved the following actions:

- Dispelling myths, stereotypes and biases of disability
- Recognising disability as possibility
- Extending boundaries, as they adjusted to the numerous losses, emotional changes,.

Individual level

The women were able to identify and respond to their own needs for development. Their sense of agency and desire to work helped the women regain their ability to dream and fulfil their roles again, their hope, their health and well-being. They were not merely passively dependent on disability grants, but they used their grants as seed money to empower themselves through informal trading and aspirations for entrepreneurial development. Their desire to work had changed their lives for the better. Many women were self-employed in the informal sector, yet still sought employment in the open labour market. Their stories provided evidence that they had acquired skills for income generation, beyond work as a means of survival. They also benefited from being positive role-models for each other as they dispelled the myth of laziness.

Family level

The women showed their resourcefulness by '*Doing a lot with a little*' in the way that they optimised their DGs, voiced their needs and fostered reciprocity. The women were proactive in voicing their needs for assistance when it came to dealing with domestic violence, financial exploitation,

economic empowerment and accessing resources for development. They voiced a need for business literacy to learn how to maximise their DG to increase their family income! They adopted strategies to manage their multiple responsibilities constructively with few resources at hand.

Community level

The women were creative in making ends meet, by extending boundaries together with CRWs, who provided relevant information and different forms of support. These boundary extensions ranged from securing food from neighbours, to DGs, accessing schooling for youth and enhancing skills development to ensure the sustainability of their small business initiatives. The vulnerability in coping with functional losses related to their impairment environmental barriers to participation create a fragile balance in meeting the physical, psychological and emotional needs in the family.

Two action stories

The two action stories illustrate the changes that occurred in the lives of the women. The first action learning story, ***Waiting for transport***, reflects the inward changes experienced by the disabled women focused on the way the women mobilised for accessible public transport. Maybe not surprisingly, the area of most difference that creates a major barrier was inaccessible public transport. This barrier affects access to skills development, jobs and other resources. Inaccessible transport means that there is little opportunity to access areas and opportunities where these aspects could be nurtured.

Through dialogue and critical reflection with the women on the reality of the situation, some of the group began to realise that their endeavours of business development depended on negotiating collective responsibility to ensure accessible public transport. The women realised that they had shared collective responsibility with the CRWs for organising transport for monthly workshops.

There was a sign of growing interdependence amongst the women as they problem-solved together. A committee was elected. The women also decided to organise transport for the monthly workshops as a small group in each area where they stayed, rather than relying on SACLA to provide the transport for everyone. The latter system had delayed the start of workshops. SACLA would organise transport for the few women who were not able to use public transport because of more severe mobility impairments. The situation of the young women with intellectual impairments was discussed to ascertain the safety of them using public transport. The suggestion was made that women travel together rather than on their own.

In summary, the action story on public transport showed how central accessibility issues are to the empowerment and inclusion of women. The current public transport system is fraught with barriers to participation, such as taxi violence and the abusive behaviour of drivers, which left women feeling emotionally vulnerable. These barriers are particularly problematic for the women, as it hampers their efforts of accessing opportunities and resources. The distances between the areas where women stay made it difficult for practitioners and members to communicate changes in what was planned and in meeting regularly as there were limited phones and transport. Action-learning enabled the women to gain confidence in decision-making as they explored choices and options for action. The women gained a sense of being in control of their destinies. They began to use collective problem solving as a strategy to mobilise for accessible public transport. The location and distance of resources, opportunities and markets necessitated confidence in planning and organisational skills. Through the narrative action-reflection workshops the women began to effect change as seen in the sub-theme *'We have to stand'*. The action story revealed the tensions and dynamics of moving from dependence and blaming to taking responsibility and self empowerment. These tensions have to be balanced to enable and sustain change.

'Making our voices heard' is the second action story illustrating the outward changes. The main plot show a sense of collective action, which grew out of their understanding of creativity as a strategy to equalise opportunities. The NAR workshops provided opportunities over a six-month period to identify and organise women into six skills development clusters. This story of the *'Abangane Choir'* demonstrates an innovative contribution to disability awareness and advocacy while at the same time showing potential for entrepreneurship. It reflects the innovative ideas that grew out of the NAR workshops, and the collaboration between the three partner organisations, SACLA, DPSA, and UCT. It was clear from the longitudinal analysis of workshop transcripts and field notes that there was an abundance and diversity of skills amongst the women, irrespective of the nature of their impairment.

We are planning that all of us, as disabled women, become part of a choir...we wish to get a person who knows drama and music to help us. We are going to practise to be good. (Small group, June 2000)

From observations of what happened at the beginning and end of each NAR workshop, the research facilitators reflected back to the women the strength of their singing and dancing skills. The women decided to form a choir that would enable them to combine their cultural skills with raising awareness on disability issues and advocacy to challenge stereotypes related to disability. The

women and CRWs performed at various community events and celebrations such as weddings, birthdays, and funerals. They began to take advantage of public events where they could market their skills as well as develop links to disability awareness and advocacy e.g. SACLA's 20th Anniversary celebrations. The development of the choir provided the women with an opportunity to meet many of their human needs such as identity, creation, affection and participation (Max-Neef, 1991), as they made the decisions about how to develop the choir's potential. They learnt how to resolve conflict related to membership and the functions that the choir would participate in, as well as build group relationships. The challenge of building group cohesion was difficult as some members attended sporadically, because they were involved in other activities. The group also experienced difficulties in accessing resources needed to plan attitude-changing strategies. The women reported that they were too far from each other and didn't have telephones to communicate any changes to plans. The group also struggled with costs of transport to get to practices, which happened twice a week. Thus there was a need to find focus to ensure commitment and accountability. They decided to have a constitution to guide membership. The members recognised the need for management and organisational development skills to build capacity to address the difficulties of working in a context of poverty.

Collaborative research on DYESL

Nine workshops were held over a two-year period. We rotated the venues for the team workshops between the four provinces. The project leader and two other team members formed the planning committee. (See Table 2 for the purpose and outcomes of team workshops)

Table 2: A summary of the purpose and outcomes of DYESL research

Dates	Purpose	Outcomes
May 2007, UKZN	Planning meeting of academics from three universities initially in study. Subsequently two other universities join	Ethical approval for research Understanding of current involvement in different sites
September 2007, UKZN	Review and reflecting on pilot phase of study and planning for next stage	In-depth interview facilitated by Pam McLaren so that three researchers could participate equally Meeting with SANPAD project manager about funding
2–3 November 2007, Birchwood Boksburg	Meeting to negotiate further partnerships with other higher education institutions and other stakeholders from	Explore the feasibility of collaborating on the study To plan logistics for pre-proposal workshop

	<p>government, DPOs, and NGOs Prof Sally Hartley, University of East Anglia and Executive Director of the CBR Africa Network shared information concerning a similar collaborative experience on establishing Community Action Research on Disability (CARD) in Uganda</p>	<p>Identifying potential sites for data generation</p>
<p>23–25 November, Umgeni Nature Reserve</p>	<p>Pre-proposal workshop to develop the proposal Joined by Prof Harry Finkenflugel as our Dutch partner</p>	<p>Consensus on title of the project, theoretical and conceptual frameworks, research questions, methodology Proposal finalized and submitted to SANPAD in February 2008</p>
<p>23–25 March 2008, Umgeni Nature Reserve Howick</p>	<p>Sustainable Livelihoods Approach (SLA) workshop to train research team on principles and background to the SLA approach</p>	<p>Building knowledge on relevant icebreakers and data-gathering methods, e.g. focus groups, interviews, time lines, Wheel of Opportunities, ox and rocks method, Venn diagram, and transit walks. Helpful readings and handouts</p>
<p>16–17 May 2008, Bains Game Lodge, Bloemfontein</p>	<p>Data analysis of focus groups, timelines and Wheel of Opportunities Free-writing sessions</p>	<p>Site orientations – each group presented a verbal sketch of their site to the team Analysis of interview transcripts; brainstorming on themes and codes Organizing information into themes for retrieval Working in teams on focus-group transcripts to identify themes and cross-references Evaluation of methodology through each group sharing their experiences of the strengths and weaknesses of their data gathering and then doing mutual problem-solving</p>

		to try and overcome weaknesses
3–6 August 2008, Geodgedact, Malmesbury	Data analysis of interviews, transect walks and Venn diagrams	Data and themes analysed Continuation of to capacity building to write an academic article Input from Prof Rachel Thibeault from Ottawa University on microcredit and CBR in African countries Ingrid of Goedgedacht Community Development Projects shared their experiences
March 2009, Kopanong, Benoni	Develop questionnaire and plan training of fieldworkers	Fieldworkers trained for 10 sites
August 2009, Kopanong, Benoni	Finalise questionnaire	
April 2010	Cleaning data	
Aug 2010	Analysis and writing workshop	
April 2011, Fish Hoek	Writing workshop	
July 2010, Stellenbosch	Writing workshop	

Findings related to strategies utilised by disabled youth for their social, economic and political development

Health component of disability inclusive development

Strategy	Barriers	Facilitators
NGOs, CBR workers, Home based carers, Students, Traditional healers	<ul style="list-style-type: none"> • Limited time • Limited money and resources to respond to needs • Inaccessibility • Disabled women can't train as traditional healers 	<ul style="list-style-type: none"> ▪ CRWs know disabled youth ▪ NGOs dealing with disabled people ▪ Home visits ▪ Garden projects ▪ Counseling and support ▪ DGs and assistive devices

Education component of disability inclusive development

Strategy	Barriers	Facilitators
Accessing local schools and day care centres	<ul style="list-style-type: none"> ▪ Physical access ▪ Attitudes – parents, staff, other children ▪ Ignorance of policy by youth ▪ Poor implementation of White Paper 6 	<ul style="list-style-type: none"> • CRWs facilitate access • Placement in schools through developmental clinics • Access for CP and intellectually disabled children

Livelihood component of disability inclusive development

Strategy	Barriers	Facilitators
Contract work	<ul style="list-style-type: none"> ▪ Poor planning and management skills ▪ Lack of suitable venue ▪ Inconsistent production ▪ Inexperienced OTs or NO OTs ▪ Poor skills for sustaining projects ▪ Decreased motivation – e.g. boring tasks 	<ul style="list-style-type: none"> • Near to residence • Simple tasks • Identified work components matched to ability • Easy mobility access • Willing factory owner

Social component of disability inclusive development

Strategy	Barriers	Facilitators
<p>Media and information dissemination</p> <p>Other Strategies</p> <ul style="list-style-type: none"> • The church • Their families • Social security networks including social workers • Disability grants • Motivational Speakers 	<ul style="list-style-type: none"> ▪ Skills development needed ▪ Limited access to info on rights 	<ul style="list-style-type: none"> • Being informed • Community radio station • Awareness raising • Information sharing used to address stigma • Increase access to opportunities

Empowerment component of disability inclusive development (systems and governance)

Strategy	Barriers	Facilitators
Transport – taxis, public road infrastructure Housing Community organisations and structures	<ul style="list-style-type: none"> ▪ Expensive, unreliable ▪ Competition in industry ▪ Taxis inaccessible ▪ Attitude of taxi drivers – unscrupulous; greedy and insensitive; mercenary ▪ Too much effort to pick up disabled people ▪ Poor infrastructure 	<ul style="list-style-type: none"> • Taxi association can be supportive

What works and why

The purpose of both studies shared in this paper focused on the participation of disabled women and youth in socio-economic development opportunities. Both studies identified the barriers faced and the strategies utilised for poverty alleviation and inequalities in human development experienced by disabled women and youth at a local level.

Narrative Action Reflection Workshops

Our study has contributed to the development of a method for generating data collectively from the lived experience of women, while simultaneously benefiting them. The method enables storytelling and action learning by marginalised groups in impoverished contexts to mobilise collectively for action to identify barriers to inclusion and strategies to them so that equal opportunities in human development is achieved. Narrative action-reflection workshops, proved to be a **catalyst for change and empowerment** in disability inclusion and human development. The process was compatible with fostering their participation in action for change. The study contributes to an understanding of how collective experiences are able to support policy implementation, so as to maximise resources and the inclusion of disabled women and youth in mainstream development opportunities. **NAR** workshops foster the **interdependency of Ubuntu**, and a **spirituality of disability** as critical dimensions of **collective agency** in the quest to create a web of possibilities for equalising opportunities for **social change** and inclusion of disabled women and youth.

Creating a network of action spaces through Action Learning

Doing is first thinking and then planning and then afterwards you develop so that the end product can be a success. But it can also be possible that the end product is unsuccessful (Small group).

Writing on the situation of poor people in the new South Africa, Barberton (1998:3) advocates that “creating action spaces...seeks to encourage people to think about and debate how the challenge of poverty and democracy... might be achieved by doing some things differently... to establish a more just socio-political, economic distribution of power”.

An action-learning approach ensured relevance, as it identified generative themes through active listening and allowed problem-posing and dialogue to create action plans for social change by the women themselves. Different writers have used different terms to refer to the cyclical process of action-learning. We used the four-step process of Hope and Timmel (1995) and Taylor *et al.* (1998), which are repeated: doing, seeing, thinking, planning.

From these newly created action spaces, the women engaged in an inward and outward journey of conscientisation regarding their beliefs and values. Collective agency comprises six aspects of social, economic, political, as well as spiritual, emotional and moral of human beings. They are all interconnected. As we recognise the human poverties that we experience at an individual level, so we can identify actions collectively that will build solidarity to enable disabled people to create a network of action spaces for their inclusion in opportunities for human development. Despite the complexity of disability and poverty, the actions that the women engaged in generate a web of possibilities. The interdependence of *Ubuntu* and a spirituality of disability (explored later) can, hopefully, deepen our understanding of how disabled youth and women are able to equalise opportunities for their development (see appendix 1 for narrative of figure 2 below).

Figure 2: We create a network of action spaces



How the strategies are conceptualized

Conceptual frameworks that informed the dynamic interchange between poverty and disability were equal opportunities, human scale development understanding of human poverties, and CBR as inclusive development. The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (UN, 1994) define the **equal opportunities** as:

“the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all, particularly to persons with disability”. (p21)

The presence of power dynamics was illustrated in my growing understanding of the essence of CBR from practice and research. As one CRW commented:

I made a pot with three legs... it is a CRW, disabled women and [the facilitators], so it is for us to cook with this pot... if one leg is broken, it can't stand on its own (CRW).

As the project leader, I journaled continuously and at one point wrote:

CBR has been about demystifying practice, professionalism and research as vestiges of power and privileges that serve only to alienate and exclude certain people. If we are not conscious of the different forms of power, we may further oppress disabled people through our practice and research. (Lorenzo, 2005:xxi)

A spirituality of disability

The spirituality of people has been dormant in human development discourse and projects, which have largely excluded disabled people. Disability enkindles an innate spirituality that becomes a source of power through the narrative on individual and collective experiences of disability. During the NAR workshops, in the women's skills in song, dance and other cultural traditions emerged vibrantly, which need to be fostered. Their spirituality infused all the workshops through their singing and rituals of prayers. Their symbolism in the creative activities should be explored to reveal the meaning and role of their spirituality in equalising opportunities. Their appreciation of interdependence and spirituality provided a source of energy needed to sustain the process of inclusion and social change. The women's experiences suggest that interdependency and a spirituality of disability need to be a driving force or catalyst to achieve equal opportunities in human development for disabled women. These changes would mean that the women experience improved access to health services, public transport, and other social systems. A spirituality of disability was a source of power in the women, as it enabled the women to see their potential, choices and hopes, as well as nurturing their emotional resourcefulness. These experiences suggest

that interdependency and a spirituality of disability need to be seen as driving forces or catalysts to achieve equal opportunities in human development for disabled women.

The importance of nurturing emotional resourcefulness was evident, as the women experienced loneliness, dependency, isolation, helplessness, abuse, exploitation, strained relationships and marginalisation. In order to equalise opportunities, disabled women need access to an effective judicial system through street committees, police and access to the courts. Economic respite should also be provided in the form of skills development for income maintenance, so as to facilitate the meeting of subsistence needs without crippling the emotional well-being of women. Social security extended to child maintenance would alleviate the burden carried by single mothers. The stories related to family life revealed the need for more attention to be given to strategies that enable respite and attendant care, which the CRW is in a good position to provide. Women need support to reinforce their strategy of voicing their need for advice and information to overcome abuse and discrimination in the family. Strengthening networks between DPOs and NGOs, as organs of civil society, for collective action to equalise opportunities through creating access to justice needs to be explored. Capacity of stakeholders for disability inclusion can be developed reciprocally through working together.

Think disability inclusion, provide information, work and learn together

Lorenzo and Joubert (2011) identified **reciprocal building of organizational capacity** and **generating collaborative relationships** for disability-inclusive development which reflected the strengths and challenges faced when multiple organizations work together over a wide geographical area on a complex research project that also builds capacity reciprocally. Recognising the COMPLEXITY of changing disability stereotypes and biases both in the disabled person themselves, their families and communities of which they are a part was a relevant outcome of both studies. Practitioners need to recognise and work with human needs and potential as a resource through doing, being and belonging

And the other thing is that things said here are developing and building us inside...the other thing is that these things are relevant to us exactly deep down in our hearts. They are encouraging us (Bongiwe).

We were encouraged as disabled women to share ideas and that is when that candlelight came up and we were then able to see (Small group)

CBR advocates for disability inclusive development for disabled people, which involves the combined efforts of disabled people themselves, their families and their communities, and the appropriate

health, education, vocational and social services. With few exceptions, CBR has been implemented in South Africa mainly through the efforts of NGOs and DPOs, with little involvement and commitment from government or universities. There is evidence that CBR is a relevant strategy for Africa in facing the challenges of poverty alleviation and the development of disabled people, if implemented by all critical stakeholders (Finkelflugel, 2004; Hartley, 2002, 2004; Hartley and Okune, 2008; Lorenzo, 2012). WHO (2010) revised the approach to CBR to focus primarily on equal opportunities and poverty alleviation.

Allan Kaplan's (1999) **six elements of organisational capacity** were helpful in doing a secondary analysis of capacity that was developed within the DYESL research team. For the purpose of this paper I am discussing the first three elements which are seen intangible but essential for elements.

1. Conceptual frameworks

Disability inclusion adopts a strong rights-based approach. The Bill of Rights in the South African constitution identified socio-economic rights, which incorporate the right to housing, health care, education, social security and employment, as basic human rights (Cilliers, 2004). The Standard Rules on the Equalisation of Opportunities for Equalisation of Opportunities for Persons with Disabilities provided the framework for disability policy development in post-apartheid South Africa. Since 1997 the White Paper on an Integrated National Disability Strategy (INDS) (ODP, 1997) states that the situation faced by disabled people in South Africa is one characterised by extreme levels of inequality and discrimination. Disabled women, especially black women and those staying in rural areas, have experienced higher rates of exclusion. The INDS provides a guide to the different ministries to ensure that the rights of disabled people are protected and promoted by recognising their contribution to development of the country.

2. Organisational attitude

Building relationships that are fundamentally inclusive was an approach we agreed to amongst team members and participants in the DYESL study. The Empowerment Cluster really of CBR guidelines (WHO, 2010) looks at the political and governance functions, with empowerment being a principle that is relevant in all five clusters. We recognised the inter-relatedness and cooperativeness as a team.

3. Culture, Vision and Strategy

Transformative leadership - shared vision, values and goals towards equal opportunities and rights. Exchange of knowledge and experiences between community workers, DPOS and academics

Appreciate collective experiences – strengths compliment each stakeholder. No one person or sector can do it alone.

Be pragmatic – action focused at local level, what people can do for themselves collectively

Learning from each other – take responsibility, learn from mistakes, stop blaming others

(Structures and systems, Individual skills and Material resources are the three tangible elements of organisational capacity.)

Negotiating principles for capacity building for disability inclusion in research between DPOs and higher education institutions (HEIs) were identified by Lorenzo and Joubert (2011) which are summarised here:

- (1) Openly acknowledge tensions in the collaborative research process.
- (2) Recognize tensions created by the diverse ways of collecting data as well as the contextual differences of the various role players and be responsive to context-specific needs.
- (3) Document experiences and disseminate findings regularly to influence policy implementation meaningful by putting it in the hands of people who could make a difference
- (4) Safeguard time for reflection and writing.
- (5) Uphold equality among the academics and community workers as each brings a diverse range of skills and abilities.
- (6) The process of relationship building is critical to becoming *shakeholders* to pull community resources and potential together into collective action and learning.
- (7) Manage the tension of time for research, other workload demands, and expectations
- (8) Trust, transparency, and a style of collective leadership ensure progress and instil confidence
- (9) Negotiate authorship of published papers, principles of accountability or paper presentations at conferences openly.
- (10) Maintain a sense of humour and patience throughout the process.
- (11) Negotiate the workload between the members of the research team as well as amongst the staff in the different “home” organizations

Human Scale Development

Max-Neef (1991) and Hope and Timmel (1995) contend that real development will only happen if all nine fundamental human needs are met. Beside subsistence, the fundamental human needs are not seen as hierarchical, but rather each need is regarded as equally important (Max-Neef, 1991). The theory looks at addressing poverty by meeting deeper human needs rather than just material

aspects, economic goods or services. The approach seeks to develop self-reliance by overcoming human poverty in all its forms. HSD theory talks about *poverties* in relation to any fundamental human need not being adequately met, not just subsistence needs (Max-Neef, 1991). HSD addresses the scarcity of resources, as human needs are seen as life forces that become resources to mobilise people to act to meet their needs. HSD adds the dimension of *synergy*, where the creative and synergic social potential that exists, but lies dormant in people, is stimulated so that limited resources are stretched further. In this way, the human capacity of people to solve their own problems is mobilised (Van Zyl, 1994).

Recommendations for scaling up

The NAR workshops have shown that if women can be helped to become competent participants in their own rehabilitation and development within the community, as well as people who have some hope and aspirations, then they will no longer be isolated and dependent. The nature of capacity building strategies to ensure meaningful skills transfer and implementation of programmes for the development of disabled women and youth should be the focus of all scaling up efforts. The co-ordinated influence of critical *shakeholders* who can contribute to human scale development involves collaboration between various stakeholders in public service, DPOs, NGOs and higher education institutions. There needs to be systematic capacity building of service providers and DPOs to use the framework as a guide for programme development in public and community service organisations.

Reciprocal building of organizational capacity for disability inclusion

The key strategy for up-scaling is generating partnerships between higher education institutions, DPOs and service providers in government and NGOs to build capacity in transformative leadership for disability inclusion (Ramphele, 2008).

The findings of the two studies reflect the need for a **co-ordinated, intersectoral approach** between government, NGOs and higher education institutions if we are serious in our intentions to remove the inequities and inequalities faced by disabled youth. Five key strategies for sustaining the livelihoods of youth through disability-inclusive development are:

- ❑ **Health** – get doctors and nurses advocating for CRWs.
- ❑ **Education** – retain disabled children through schooling to be able to access tertiary education.
- ❑ **Financial** –invest resources in skills development for entrepreneurship and open labour market jobs

- ❑ **Social** – create strong family and community networks. opportunities, through sport and recreation, religious organisations etc
- ❑ **Physical** – accessible public transport as well as communication and information systems

Capacitating community based workers²

CBWs should be trained as catalysts for change to address impairment and development needs (Lorenzo, 2012). They are from the community and therefore know the people, resources, referral systems, build trust. Essential aspects of their work include:

- Restoring the humanity of disabled persons
- Building family support
- Accessing information on financial resources and skills development opportunities
- Bridging the communication gap across sectors at local level

Implications for curricula changes at higher education institutions

Leadership of all faculties at higher education institutions need to become more inclusive of disability issues. Three signposts for this journey are suggested.

Signpost 1: Redraw images of disability identity collectively

The action stories challenged the stereotypes and stigmas related to a disability identity. Small changes were happening all the time, from one workshop to another, both at an individual and collective level. The strength in their identity could be contrasted with the vulnerability that one would usually expect. It was evident that the women found inward strength by gaining confidence through friendships that developed as a consequence of a network of action spaces. The women demonstrated how telling their story illuminated the stereotypes and biases related to disability in a way that provided support for collective action to address oppression and discrimination (Villa Vicencio, 1995). Coleridge (1993) also claimed that change has to begin with those who want change: women and their allies. The women became catalysts as they confronted the barriers that hindered their participation in activities and events. They engaged in opportunities for skills development and occupational engagement that may not have occurred if they had not been disabled (Lorenzo, 2004; 2005).

² [CBWs as a strategy to up-scale efforts to address poverty and inequality experienced by disabled youth will be elaborated in paper by Ermien van Pletzen, Theresa Lorenzo and Margaret Booyens]

Signpost 2: Generate networks of action spaces for disability-inclusion

Women created a different story about themselves, their families and communities through interacting collectively and reflecting on action taken and lessons learnt. Inclusion of the women into mainstream development initiatives is feasible, if stakeholders appreciate differences and build on commonalities. Diversity is seen as race and gender, why not disability? The two action stories suggested that there was not much about these stories that would distinguish the women from other women. Oppression is a common experience amongst women. The women's ability to change their personal circumstances and recognise changes in others increased. The women appreciated the power of listening to one another's stories. Learning to listen reinforced the importance of building supportive, inclusive communities where personal development, emotional wellbeing and social harmony could be nurtured (Broodryk, 2002; Tutu, 2004). The most valuable resources the women discovered were the human experience and human spirit that gave them the ability to take risks. The language of light dispelling darkness and bringing hope was evidence that they became catalysts for change.

Signpost 3: Equip all graduates with competences to facilitate equal opportunities to address social inclusion and disability discrimination.

Generate disability inclusion in teaching and research across all disciplines and faculties at higher education institutions. There is a need to lobby policymakers and higher education institutions for inclusion of disabled people in mainstream development initiatives, particularly lobbying for accessibility of transport and information as a precondition for equal opportunities.

Capacitate human and intellectual resources for disability-inclusive development through students and staff involvement in service learning and social responsive projects

In closing:

When we choose to see situations as opportunities, when we look within for answers and guidance, we find our outer world reflects our inner conditions. As we become more gentle and harmonious so do our outer worlds. As we become more adventurous and expansive, so do our worlds. We are co-creators not victims of circumstances! (Bryan and Cameron, 1998)

References

- Barberton, C. (1998a) Introduction. In *Creating action space: The challenge poverty and democracy in South Africa* (edited by C, Barberton, M. Blake, and H. Kotze) Cape Town: David Philip Publishers. 3-10.
- Broodryk, J. (2002) *Ubuntu: Life lessons from Africa*. Pretoria: Ubuntu School of Philosophy.
- Bryan, M. and Cameron, J. (1998) *The artist's way at work*. London: Pan Books.
- Cilliers, L. (ed) (2004) *Disability Policy in action: South Africa's Integrated National Disability Strategy explained*. Cape Town: DPSA
- Coleridge, P. (1993) *Disability, Liberation and Development* U.K.: Oxfam.
- Finkelflugel, H. (2004) *Empowered to differ*. Rotterdam, Netherlands.
- Gueye, S. P. (1999) African renaissance as an historical challenge. In *African Renaissance* (Edited by Makgoba, M. W.) pp243-264. Sandton: Mafube Publishing and Cape Town: Tafelberg Publishers.
- Hartley, S. (ed) (2002) *CBR: A participatory strategy in Africa*. London: University College London, Centre for International Child Health.
- Hartley S and Okune, J (2008)
- Hermanus, K. (ed) (2000) *Building an inclusive community: a disability perspective*. Cape Town: SACLA Rehabilitation Project.
- Hope, A. and Timmel, S. (1995) *Training for Transformation: A Handbook for Community Workers Revised Edition*. Zimbabwe: Mambo Press.
- Hudson, T. (1995) *Signposts to spirituality: Towards a closer walk with God*. Cape Town: Struik Christian Books.
- Lorenzo, T. (2004) Equalising opportunities for occupational engagement: disabled women's stories. In *Transformation through occupation* (edited by R. Watson and L. Swartz) London and Philadelphia: Whurr Publishers. 85-102.
- Lorenzo, T. 2010 Listening spaces: connecting diverse voices for social action and change. In *New approaches to qualitative research: Wisdom and uncertainty*. Edited by M.Savin-Baden and C.H. Major. London: Routledge
- Lorenzo, T. (ed) (2012) *Marrying community development and rehabilitation: aspiration or reality for disabled people. Disability Catalyst Africa Series 2*. Cape Town: Disability Innovation Africa with Disability Studies programme, UCT.
- Lorenzo, T. van Niekerk, L., and Mdlokolo, P. (2007) *Negotiating partnerships Disability and Rehabilitation*

Lorenzo, (ed) 2012 Marrying community development and rehabilitation. *Disability Catalyst Africa Series 2* Cape Town: Disability Innovations Africa with Disability Studies Programme, UCT

Lorenzo, T. and Saunders, C. (1999) A general evaluation of the SACLA Rehabilitation Project. Cape Town, October (unpublished).

Lorenzo, T and Joubert, R (2011) Reciprocal capacity building for collaborative disability research between disabled people's organizations, communities and higher education institutions. *Scandinavian Journal of Occupational Therapy*. 2011; 18: 254–264

Lorenzo T and Cramm, JM (2012) Access to livelihood assets among youth with and without disabilities in South Africa: Implications for health professional education *South African Medical Journal* 102 (6): 578-581

Loveday, M. (1991) CBR workers: a South African training manual. Cape Town: SACLA Health Project.

Max-Neef, M.A. (1991) *Human Scale Development*. London: The Apex Press.

Nelson, N. and Wright, S. (eds) (1995) *Power and participatory development: Theory and Practice* London: Intermediate Technology Publications.

ODP (1997) White Paper on an Integrated National Disability Strategy_(INDS) Rustica Press, Pretoria

Ramphele, M. (2008) *Laying our ghosts to rest: dilemmas of the transformation in South Africa*. Cape Town: Tafelberg

Saunders, C. (1998) Evaluation of Masiphatisane Disability Forum. Report for SACLA Rehabilitation Project. Khayelitsha, Cape Town.

Taylor, J., Marais, D. and Heyns, S. (1998) *Community participation and financial sustainability. Action Learning Series – case studies and lessons from development practice*. Cape Town: Juta.

Tutu, D. (2004) *God has a dream: A vision of hope for our time*. South Africa: Random House.

Van Niekerk, L., Lorenzo, T. and Mdlokolo, P. (2006) Understanding partnerships in developing disabled entrepreneurs through Participatory Action Research. *Disability and Rehabilitation*

Van Zyl, J. (1994) What is Human Scale Development? A brief overview. Mowbray, Cape Town: The Network for Human Scale Development (Southern Africa).

WHO (2010) *CBR Guidelines* Geneva: WHO

Appendix 1 – Narrative of Figure 2: We create a network of action spaces

We gain confidence through collective action

There were three aspects to gaining confidence through collective action, namely, 'we nurture friendships', 'we unmask violence' and 'we generate a power base'. Each aspect is described briefly.

We nurture friendships

Telling stories about their everyday activities and the different opportunities for skills development that they engaged in revealed the emotional changes that the women experienced. They gained confidence through friendships that formed during the PAR study, which increased self-esteem and self worth. The experiences echoed the words of Gueye (1999) that no future or African Renaissance could be envisaged if people felt psychologically defeated because they had lost their confidence in themselves and their ability to change their own situation according to their own needs. Many writers on development in South Africa have found **self-confidence** to be a key to capacity development and sustainability (Hope and Timmel, 1995; Kaplan, 1998; Meulenberg-Buskens, 1996; Roodt, 1995; Taylor et al., 1998). Identity as a matter of 'belonging' was evident as they overcame their sense of personal isolation and engaged in actions. Hudson (1995) speaks of "gifts of friendship" that are developed through individual and collective struggles, as "belonging signposts the route towards becoming" (p80). Support and trust was built as friendships developed. The women regained self-respect as they learnt to recognize latent potential within themselves and others. There was a growing self-awareness about their abilities to provide for themselves and their families as well as to re-engage in familiar and known roles. Women remarked on the renewed dignity they found from participating in cultural ceremonies again. Regaining respect produced a strong sense of hope in the women that they would succeed.

We unmask violence

Telling their stories gave the women the strength and confidence to support each other with problem-solving in different contexts. As research facilitators, we were often overwhelmed by the high incidence of violence and abuse experienced by the women. Creating networks of action spaces had potential, as synergistic satisfiers (Max Neef, 1991), to meet many of the human needs of identity, affection, understanding, protection, participation and freedom, which had been violated by various forms of exploitation. The women most frequently asked for more advice about dealing with violence, which suggested that the community structures they reported were ineffectual. Thus, the women were often left isolated in their homes or had tried to fight the violence alone. By

creating action spaces for the women to speak about their experiences of violence that occurred in different forms, they were able to break the silence and receive support and solutions from others who had similar experiences. DPSA organized several workshops with consultants on these issues. Hope in the future lay in women making their voices heard through organising collectively so that negative attitudes about disability were uprooted.

We generate a power base

The disability rights movement prioritises the development of community-based support systems to provide an organized power base for disabled people from which to build a partnership with professionals (Finkelstein, 1993; Coleridge, 1993). The Disabled Women's Development Programme of DPSA provided a power base from which the women were able to organise themselves and access opportunities (Cilliers, 2004; Cockburn, 2003). Marjorie, the chairperson of DWDP and a research co-facilitator, provided a strong role model as a disabled woman herself, which enabled other women to become catalysts of change as well. The number of positive role models among the women themselves multiplied. There was also appreciation for the role of SACLA's CRWs, themselves mothers of disabled children, as catalysts of change. As research facilitators, we were able to request that the CRWs report critical issues at their weekly team meetings. Following these reports, counselling and home visits with one of the practitioners such as a social worker or occupational therapists at SACLA or another NGO was arranged. DPSA was also able to organise relevant workshops in response to the expressed needs, which strengthened the women's strategies used to carry their load. Lorenzo and Buchanan (2006) found that structures such as disabled peoples organizations, parents' support groups, playgroups or day care centres, and income generation projects provided an organized power base for disabled people from which to build a partnership across different sectors.

Information sharing was as a key strategy to create group cohesion for collective action. The women needed adequate time and opportunity to access information that service providers already have. They needed time to learn how organisations work and the way that services are set up. Thus, the challenge was to find ways that the women were able to act together, not once but consistently, to get ahead collectively. Their emotional growth enabled the women to build strong, reciprocal partnerships (social harmony) with other disability organizations, civil structures and health and social services, which would contribute towards human development. The building of social harmony required investment of trust and social skills of all players in the process.

A pattern of interactions between the women and the CRWs, as well as the research facilitators, raised tensions related to the roles different stakeholders assume, or maybe more accurately, that

they move between. There was always the risk that the dynamic in power relations between the women and research facilitators could lead to mutual deception because of the hope of gaining something, or fear of penalty. The practice of participation sometimes felt cosmetic where the right language or terminology was used, but there was little change in behaviour. While the women respected one's level of education, they were cautious of their vulnerability to exploitation, and traditional cultural values were paramount. Older people were shown respect by younger people. We remained open to the women questioning us, and being accountable to the group in decision-making processes. Women grew in their ability to listen, which had positive ramifications for collective action. Nelson and Wright (1995) comment that participation involves looking at a shift in power and working in partnerships. Power in this sense was seen as a description of a relation, not a 'thing' that people 'have'. In the national context, political changes have not been matched by economic improvement for women generally (Meer, 1998). Unfortunately, the new legal changes in South African laws such as the Labour Relations Act, the Employment Equity Act and the Basic Conditions of Employment Act had not yet translated into reality for the women in this study.

Creating a network of action spaces involving similar projects strengthened the women to achieve in their initiatives. Such collective action was common among women generally during the struggle against apartheid (Meer, 1998). *Stokvels*³ were another common strategy of collective action in the Black communities as a way of building up seed money or initial capital to offset a new business venture (Broodryk, 2002). The groups used the same strategy to collect money from each member of the group, which ranged from R5 – R30, on a monthly basis as a means of building up financial capital. Each group appointed a supervisor and treasurer to keep account of the funds.

We learn to listen

Two processes that occurred as the women learnt to listen to each other were 'we foster healing' and 'we take risks'. These strengthened the network of action spaces.

We foster healing The power of learning through listening to each other helped to heal the relationship between the women and their siblings, spouses and children. There was an honesty and truthfulness as women shared their stories, listened and responded to each other in a way that generated respect and dignity. Negative experiences related to disability were healed through engaging in everyday activities. The sense of solidarity and reciprocity that developed during the workshops emerged as they began to participate in local development projects with other non-

³ A traditional means of collective savings where each member contributes monthly, and one member receives the savings on a rotational basis.

disabled women (Lorenzo *et al.*, 2002; Lorenzo, 2004). Their sense of isolation was broken as they found their voice and shared compassion.

We take risks to increase choices Risk taking also grew as the women discovered more strategies to meet their needs collectively. Flexibility in the workshops helped explore the dynamics of dependence, helplessness and vulnerability as power. The women recognised the changes that happened through their own actions. They took the risk of showing their vulnerability while honouring the dignity of others. We reversed the way we taught, learnt and evaluated progress in order to change the situation of poor people. We learnt the importance of embracing mistakes by sitting, observing, asking, listening and reflecting on everyday practice and seeing the women as active participants rather than passive recipients (Lorenzo, 2003; Priestley, 1999; Read, 2000). Real empowerment and self-development happened when the women were given the “space and freedom to fail and learn from their failures on their own” (Coleridge, 1993:113). Such flexibility in working together allowed for exploration of a diversity of needs and ideas. The approach also encouraged exploration of different experiences and perceptions of power in partnerships between professionals and DPOs.

Figure 2: We create a network of action spaces

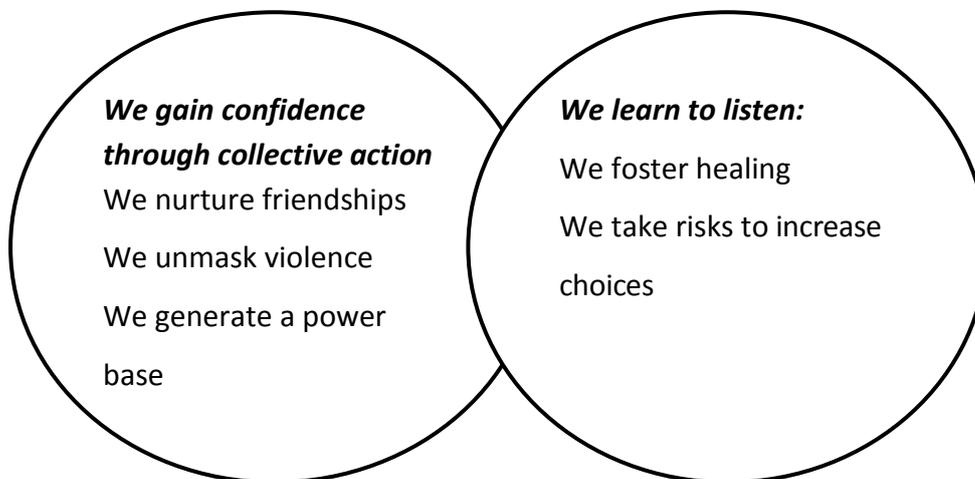




Figure 13.
 Narrative action research workshops as a method and a strategy