A narrative report on an evaluation of the partnership between Disabled Children's Action Group (DICAG), South Africa and Norsk Forbund for Utviklingshemmede (NFU), Norway during the period 1997–2004

"Disabled people's organisation to disabled people's organisation:

It was a completely different type of chemistry really in the relationship."

(PARTICIPANT)

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PREFACE

The co-operation agreement between NFU and DICAG ended on 31 December 2004. An evaluation of the partnership has been planned as an important integrated part of the co-operation, so that both NFU and DICAG have the possibility to adjust the course of their work according to the suggestions made by the evaluation.

DICAG is described as a cross-disability national organisation of parents of children with disabilities in South Africa, whose key role is as an advocacy and children's right organization. They monitor the implementation of plans on all levels of government, to contribute effectively to the policy process of government in the interest of disabled children and to participate in activities that seek to improve the quality of life of children with disabilities and their families. DICAG engage in activities at the national, provincial and local level in South Africa.

Norsk Forbund for Utviklingshemmede (NFU) has had a partnership agreement with DICAG since March 1997. Funding was originally earmarked for DICAG's Provincial Advocacy Leadership and Policy Development Programme (PALP). From 1999 the funding was directed toward DICAG in general. Since an evaluation in 2001, the major task of NFUs support to DICAG has emphasised support for the general organizational development, its role as an advocacy organisation and the advocacy skills of parents, particularly at the local level. This shift in NFU's strategy and plan was supported and contradicted by the statement below.

> *Just exactly that, that whilst we have some many progressive qualities within the country, DICAG has a role to play in Africa. With our experiences in the last 10-11 years of democracy we have a definite role, but also capacity to share with other parent organizations on the continent. Also that when it come to children with disabilities, yes we do have inclusive education polices. But not all children are able to access that. And so there will always be a place with in special education or day care centre for a child and it is our role as an advocacy organization to make sure that child receives that support (parent).*

Consistent and constant reflection between international funders and local NGO's of the goals and strategies is necessary, specifically, for a South African environment which is consistently in a state of flux due to the democratic changes. These reflections should take cognizance of the needs of both parties. It is hoped that with this approach meaningful relationships could emerge.

EXECUTIVE SUMMARY

Section1: Background and context

When DICAG started as a programme of DPSA in 1993, South Africa was in a period of transition toward a massive political transformation that began, rather than ended, with the democratic elections on 1994. Children with disabilities, particularly those living in poverty, were one of the most vulnerable groups.

The advocacy process of the disability movement in South Africa was well timed and effective. The rights of the disabled child were reflected in the various key government policy documents. Despite the development of progressive policy, the implementation has been far from unproblematic.

The Division of Occupational Therapy, University of Cape Town and the Centre for Rehabilitation Studies of Faculty of Health Sciences of Stellenbosch University were given the task to evaluate the partnership between DICAG and NFU (See Appendix for Terms of Reference).

It was intended that DICAG would use the evaluation to further work on issues where the organisation needs strengthening. It was intended that NFU would use the evaluation to strengthen its existing and future international work, particularly their co-operation with parents' organisations and networks. The evaluation will be conducted during the last quarter of 2005 (September-December).

The aims of the evaluation:
1. To explore the achievements of the DICAG-NFU's partnership since 1997.

2. To determine strategies for sustainability in order to assess DICAG's institutional viability nationally and internationally.

Section Two: **Theoretical reflections**

This section provides a review of literature related to five key theoretical concepts that informed the evaluation within a human rights framework: poverty and human scale development, HIV/Aids, gender issues, advocacy and service delivery, including a brief mention of equalising opportunities through community-based rehabilitation. These considerations are also relevant to and could inform DICAG's work in the future.

Section Three: Methodology

The evaluation team used a naturalistic qualitative research approach, because it would allow for a flexible yet in-depth inquiry. The methodology was descriptive and used both qualitative and quantitative methods.

Given the huge disparities in resources throughout South Africa, it was proposed that the evaluation was conducted in both a rural and urban setting. Therefore, the Western Cape (relatively well resourced) as well as the Eastern Cape (far less resourced) was selected as sites for the evaluation.

There were four methods of data generation, namely: Document review; Key informant interviews; In-depth interviews; Focus group discussions. The interview schedule was derived from the TOR, outcomes of the document analysis and Kaplan's (1999) organisational capacity theory that identifies the features of six stages of organisational life: conceptual framework, organisational attitude (culture); vision and strategy; structures and procedures; individual skills, abilities and competencies; and material resources.

Section Four: Findings of Document Review

Findings were linked to the framework of organisational capacity (Kaplan, 1999).

   1.   Conceptual framework
DICAG put emphasis on issues of social justice, the protection of human rights and development opportunities for people with disabilities (PWDs) within the context of the African Decade of Disabled People. The new-found democracy was recognized as a fragile situation that needs to be sustained by civil society so as to develop policies to address the inequities of the past, particularly the consequences of poverty.

   2.   An organizational "attitude"
It seems that the differences in cultural and social contexts of disability between South Africa and Norway were not clearly communicated or understood related to the purpose of the daycare centres. These different frames of reference led to tensions in understanding the roles of day care centres and advocacy. There was a high turnover of staff in DICAG and NFU that could contribute to lack of confidence, competence and capacity.

   3.   Organizational vision and strategy
The vision and strategy of DICAG as a DPO has been focused on building capacity of local parent branches to engage in partnerships with the public and private sector as well as professionals. DICAG had a vehicle to build the skills of parents as advocates through supporting the establishment of day care centres. NFU's main concerns seem to be with the relationship between the administration and the membership, and the connections between the national, provincial and local branch levels. Frustration seems to be directed at these

issues rather than a conflict between development activities and advocacy. Overall, partnerships and information to prompt action for transformation have been identified as key strategies. However, communication systems were unclear and there was inadequate organizational support to carry out roles.

4. Organisational structures and procedures
The distribution of membership across the provinces indicates that DICAG is clearly a national organisation, with the Eastern Cape, North West Province and Mpumalanga having the strongest membership in terms of numbers. While national and provincial structures appear to be co-ordinated, there is a need to focus on the link with local branches. There have been fluctuations in membership prior to 2001, but a steady growth was evident from 2002. Role confusion and conflict of responsibilities reflect a need for clarification between different committees: national council, national executive committee, provincial development team meetings; provincial executive committee, local branches.

5. Individual skills, abilities and competencies
Documents showed that most advocacy work appears to be conducted at national and provincial. The reports seem to reflect that local group members appear relatively ill-equipped to carry out advocacy themselves. It was evident that there was little consistency of training from one year to the next and there does not seem to be an overall plan. The link between training activities, advocacy and organizational development needs to be more clearly defined.

6. Material resources
In the absence of financial sustainability, tensions and lack of motivation between members occurs (Philpott and McLaren, 1999). These line items covering the different activities were divided into categories focused on: advocacy, resources, governance, specified training, networking, salaries and administration. The documents revealed that accessing resources to support day care centres was an obvious area requiring sustained advocacy. Funders and government need to consider issues of financial support in an organization run by volunteers living in impoverished contexts. Limited funding and capacity has made visibility of DICAG difficult. Material help was needed as much as capacity building. The documents did not reveal any clear strategy regarding fundraising.

Section 5: Findings from interviews and focus group discussions

1. The complexities of poverty

Poverty emerged as a significant challenge to organisational capacity as it undermined access to resources, which led to the breakdown of trust between the different role players in the partnership, i.e. the leadership, the staff, the members and the funder. It was also evident that there were different interpretations of poverty.

2. Bottle-necking of information networks hampers organisational ownership

Information dissemination was seen as an essential tool for advocacy and the development of local branches. Communication was identified as a major stumbling block towards fostering ownership of local parent branches (LPB) initiatives due to the vastness of South Africa. No finances at local branch level hindered information dissemination. However, there were limited financial resources available.

3. An organisation in a state of vulnerability

There was an emerging sense of loss of trust and vulnerability within DICAG as an organisation. Members felt that "*even though we did what they wanted"* the funders were "*pulling out".* Such comments reveal an absence of ownership. In some areas, the leadership appeared to be distancing themselves and speaking as if they were outsiders, thus creating a missed opportunity for a constructive dialogue.

There were two responses to DICAG's state of vulnerability: on the one hand, a state of panic that resulted in energy to act; on the other hand, a state of despair that led to blaming between the leadership, staff and local branches.

4. Pride in DICAG's achievement

When DICAG members stay true to their values, there is satisfaction and growth at different levels. DICAG had been able to gain recognition from local through to international arenas. Members grew in confidence through mutual sharing and exchanges as a strategy for horizontal learning.

5. Tensions related to diversity issues

DICAG as an organisation mirrors the tensions related to issues of diversity, namely, gender, race, politics, and class.

6. Excited and confused leadership

It was evident that DICAG membership and funders experienced a range of emotions in developing the structures of the organisation at different levels as roles. It became apparent that while the achievements of DICAG were numerous there was also confusion about how the organisation should achieve advocacy through their different partnerships. There was always a tension in explaining the role that day care centres versus local parent branches should play in relation to one another. The drying of funds impacted negatively on the functioning of the PECs or local parent branches. Effective communication systems are essential.

7. Conflict in funding strategies for enhancing people-centred development

While NFU suggested the development of local branches there appeared to be

insufficient infrastructure and resources committed to run the local Parent branches. NFU consultants might have been more costly than using local consultants.

Section Six: Lessons Learnt and Recommendations

1. A broad-based communication strategy and infrastructure are essential and non-negotiable
DICAG's leadership and membership need to develop effective strategies for communication so as to avoid perceptions of being dominated, undermined or marginalised. It is also essential that values and beliefs be clearly communicated across the diversity of languages, cultures and impairments.

2. A conceptual framework for the organisation needs to be developed
While no one would argue that the core to sustainability is effective organisational development and capacity, there are a number of levels to such capacity development that need to be explored, analysed and agreed to. The global experience of funders could strengthen DICAG's contribution at all levels of governance. A vital component that needs to be considered, clarified and strengthened is the area of youth development. A new lease of life is needed at leadership level and strategic planning of this process that would take the organisation forward.

3. Managing boundaries
There is no doubt that continuous dialogue between all role players and stakeholders including funders on issues of diversity and difference will help to address feelings of vulnerability, as members and leadership gain skills in managing boundaries between the emotional, social, physical and political dimensions evoked by disability.

4. Optimal use of human resources
The complexities of poverty mean that parents and children as human beings are the richest resource at DICAG's disposal. This resource needs to be nurtured individually for the collective good of DICAG, the nation and the African continent. Roles and responsibilities need to be clarified as new branches are developed and new members join.

5. Partnerships and alliances as a key for sustainability and continuity
Partnerships across the different sectors need to be harnessed. Co-operation between DPOs and alliances with organisations addressing common issues need to be fostered.

6. Documenting and disseminating experiences for the development of DICAG
Dialogues related to learning experiences need to be documented and published widely. Partnerships with research organisations and higher education institutions could foster this capacity if effectively harnessed.

LIST OF ABBREVIATIONS

CBR   Community-based rehabilitation

DICAG   Disabled Children's Action Group

DPO   Disabled People's Organisation

DPSA   Disabled People South Africa

ECD   Early childhood development

HSD   Human scale development

NC   National council (DICAG)

NEC   National executive committee (DICAG)

NFU   Norsk Forbund for Utviklingshemmende

NGO   Non-governmental organisation

PEC   Provincial executive committee (DICAG)

SECTION 1
BACKGROUND AND CONTEXT

Introduction

When DICAG started as a programme of DPSA in 1993, South Africa was in a period of transition towards a massive political transformation that began, rather than ended, with the democratic elections in 1994. There existed, at this time, enormous backlogs in the provision of services for vulnerable and disadvantaged groups. Children with disabilities, particularly those living in poverty, were one of the most vulnerable groups. The process of transformation, guided by an adherence to human rights principles, created the opportunity for pressure groups, such as DICAG, to lobby for the rights of disabled children. However, there was at the same time a recognition that the conditions under which disabled children were living could not be left unattended and there was also an attempt to fill the gaps (Philpott, 2004).

DICAG is described as a cross-disability national organisation of parents of children with disabilities in South Africa. It is an advocacy and children's rights organisation that considers its key roles as:

- Monitoring the implementation of plans on all levels of government;
- Contributing effectively to the policy process of government in the interest of disabled children; and
- Participating in activities that seek to improve the quality of life of children with disabilities and their families. (NFU, 2005)

The policy environment

The advocacy process of the disability movement in South Africa was well-timed and effective. Their contribution to the rights of the disabled child was reflected in the following key documents:

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- The *South African Constitution* which ensures the right of equality to all people; as well as the rights of children under 18 to basic nutrition, shelter, basic health care services and social services; and to be protected from maltreatment, neglect, abuse or degradation, as well as the right to basic education (Republic of South Africa, 1996).
- The *Integrated National Disability Strategy* which moved the understanding of disability into a social model whereby the barriers within society become the focus for action as opposed to the rehabilitation or cure of the disabled individual being the sole means of intervention (OSDP, 1997).
- The *White Paper for the Transformation of Health Services in South Africa* which provides a comprehensive Primary Health Care (PHC) package for all children, ~~including free~~including free health care at the primary level for all children who use the public sector facilities (Department of Health, 1997).
- The *Education White Paper 6: Special Needs Education – building an inclusive education and training system* which states that in an inclusive education and training system, a wider range of educational services will be created in line with what learners with disabilities require. This means that inclusion focuses on overcoming barriers in the system that prevent it from meeting the full range of learning needs. The focus is on the adaptation of the environment/teaching materials, and support systems available in the classroom (Department of Education, 2001).
- The *National Programme of Action for Children* which is a co-ordinating campaign that sets specific goals for the survival, protection and development of children within a children's rights framework (Office on the Status of Children, 1996).

Despite the development of progressive policy, the implementation of these rights in the South African context has been far from unproblematic. Philpott (2004) highlights the barriers that disabled children still face and identifies the following shortfalls:

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- There is still a high level of exclusion from education and early childhood development (ECD) services.
- There is some improvement for provision of health services within PHC but access to rehabilitation services remains poor.
- There is insufficient protection for children with disabilities from abuse within the family and the community.

The *White Paper on the Integrated National Disability Strategy* (OSDP 1997, 1997) embodied the vision of a "society for all", whereby all people with disabilities are seen as citizens with rights, and not as helpless and tragic victims. It is estimated that over 14 million children in South Africa currently live in conditions of extreme poverty and deprivation[1]. Given that approximately 4% of the population have disabilities, and given the fact that disability is both a cause and consequence of poverty[2] – the situation of children with disabilities and chronic diseases can well be described as *an emergency submerged*.

The birth of a disabled child, or the occurrence of disability in the family, often places heavy demands on family morale and thrusts it into deeper poverty. This inherently results in separation and social exclusion of disabled youth and their families from mainstream activities. Exclusion and poverty seriously hinder the development process and closes the doors to any possible integration in society, thereby presenting dilemmas to the disabled and their families regarding their ability to make choices in life.

Living in remote rural areas or informal urban settlements, in situations of poverty, often means that children with disabilities and chronic diseases have very limited access to the services that they require. A consequence of this is

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[1] Streak estimated that they live below a poverty line of R490/month per capita. (Streak, J. (2002) Child Poverty Monitor, IDASA - Budget Information Service).
[2] Poor maternal nutritional status, lack of health (antenatal) services and conditions of severe poverty directly contribute to higher morbidity. In addition there are numerous costs - such as medication, visits to health facilities and assistive devices - which mean that disability makes financial demands on the resources of a household. Mothers are often excluded from other development activities because they are occupied with caring for their disabled child.

that many disabled young people are not able to access development/training programmes or work opportunities, because of a very limited formal education.

Given the history of marginalisation and exclusion of disabled children with regards to service provision, it is essential that organisations for parents of disabled children pay heed to the development of advocacy programmes that will assist them with monitoring the extent to which inclusion is being implemented so as to safeguard their disabled children's rights.

It is sometimes argued that inclusion means *treating all children the same*.[3] The problem with this arises when one recognises that the playing fields are not level, and that certain provisions are not being made to ensure that all children can participate equally. Therefore, it will be difficult for parents of disabled children to disassociate themselves from the development of advocacy issues. All stakeholders, including donor agencies, have an obligation to redress the effects of discrimination towards poor disabled children and their parents.

Stone[4] (2001) concurs with this by asserting that to understand survival means thinking about disability in relation to poverty and development. It also means to understand that social change involves identifying how a society views and responds to impairment in ways that affect disabled people, and often their families too.

Background to the evaluation

DICAG's development goal is that an increased number of children with disabilities will be empowered and live and fully participate within conducive,

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[3] Inclusion does not mean that disabled children should just slot into an unchanging society. This denies both disability and difference. It is about disabled children having their needs met and their rights protected in an adapting society. Most importantly, disabled people (both adults and children), should be involved in shaping an inclusive society (Save the Children Fund UK 2000).

[4] Stone, E. (2001) A complicated struggle: disability, survival and social change in the majority world. In Priestley, M. (ed) (2001) *Disability and the Life Course (Global Perspective).* Cambridge University: UK.

inclusive and integrated environments that enable them to feel equal, protected, accepted and adequately cared for.

By the end of 2004 DICAG had 3 151 officially paid up individual members, some of whom are individual parents of children with disabilities, some are children, with approximately 5% associates and 10% interested individuals. Of the parents 1 200 have grouped themselves into 86 local parent branches.

Norsk Forbund for Utviklingshemmede (NFU) has had a partnership agreement with DICAG since March 1997. Funding was originally earmarked for DICAG's Provincial Advocacy Leadership and Policy Development Programme (PALP). From 1999 the funding was directed towards DICAG in general. An external evaluation in 2001 emphasised the need for DICAG to strengthen and polish its role as an advocacy organisation. This has since become the major task of NFU's support of DICAG, with the emphasis on supporting the general organisational development, DICAG's role as an advocacy organisation and the developing the advocacy skills of parents, particularly at local level. In addition to being an advocacy organisation, DICAG's local parent branches also run day care centres.

NFU is a national advocacy organisation that fights for the inclusion of persons with developmental disabilities in society. NFU insists that it is the ultimate responsibility of government to provide the services required to ensure that every individual has an equal opportunity for participation. NFU's development co-operation reflects these aims. NFU provides support to democratic, membership-based parents' organisations or networks that advocate for the full participation and inclusion of people with developmental disabilities and children with disabilities. NFU supports capacity building and organisational development, but does not support service provision or service-oriented programmes.

The co-operation agreement between NFU and DICAG ended on 31 December 2004. An evaluation of the partnership had been planned as an important

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integrated part of the co-operation, so that both NFU and DICAG would have the possibility to adjust the course of their work according to the suggestions made by the evaluation.

A description of the evaluation

The Centre for Rehabilitation Studies of the Faculty of Health Sciences at Stellenbosch University and the Division of Occupational Therapy, University of Cape Town were given the task to evaluate the partnership between DICAG and NFU (See appendix 2, pg 67 for terms of reference)

Use of the evaluation

It was intended that DICAG would use the evaluation to further work on issues in the organisation that need strengthening. This might involve both polishing the structures as a democratic membership-based organisation, and also their advocacy skills. DICAG would also use the evaluation to work towards strengthening the sustainability of the organisation.

It was intended that NFU would use the evaluation to strengthen its existing and future international work, particularly their co-operation with parents' organisations and networks. Thus the aim of the evaluation would be to assess the relevance of objectives, efficiency, effectiveness, impact and/or sustainability of NFU's international work.

The Evaluation Team

A team of four researchers conducted the evaluation:

- Ms Gubela Mji: Director and senior lecturer at the Centre for Rehabilitation at Stellenbosch University;
- Ms Siphokazi Gcaza: Senior lecturer at the Centre for Rehabilitation at Stellenbosch University;
- Dr Theresa Lorenzo: Senior lecturer at the Division of Occupational Therapy in the School of Health and Rehabilitation Sciences at the University of Cape Town; and
- Mrs Judy McKenzie: Research associate from East London.

The **aims** of the evaluation were:
1. To explore the achievements of the DICAG-NFU partnership since 1997; and

2. To determine strategies for sustainability in order to assess DICAG's institutional viability, both nationally and internationally.

The **principal objectives** of the evaluation were:
1. To review DICAG's development as an organisation and to assess the scope and impact of its lobbying and advocacy work since 1997; and
2. To assess NFU's approach and contribution on all levels towards the development of organisational structure and content of DICAG (national, provincial and local).
3. To assess DICAG's long-term capacity and plans of sustainability as an advocacy organisation and make appropriate recommendations for future institutional sustainability.

Duration of the project

The evaluation would be conducted during the last quarter of 2005 (September–November). Prior to visiting the field, the evaluator(s) would read through available documentation and become familiar with the goals and strategies of DICAG, the development co-operation strategy of NFU and the agreements that

exist between the parties.

SECTION 2
THEORETICAL REFLECTIONS

The objectives of the Reconstruction and Development Programme will not have been realised unless we see in practical terms the condition of women in South Africa changing for the better, and that they have the power to intervene in all aspects of life as equals.
(President Nelson Mandela, 1994)

Introduction

This section explores theoretical reflections related to the five key concepts that informed the evaluation within a human rights framework: poverty and human scale development, HIV/Aids, gender issues, advocacy and service delivery. The review includes a brief mention of equalising opportunities through community-based rehabilitation. These considerations are relevant to and could inform DICAG's work in the future.

The impact of poverty

Development co-operation between NGOs and governments – locally, nationally and internationally – has been driven by the agreed purpose to combat poverty. In a review of community-based rehabilitation (CBR) programmes, Stienstra *et al.* (2002) boldly claim that poverty alleviation cannot be achieved if disabled people are excluded. Health and social issues are exacerbated by a situation of poverty.

According to Nomdo and Kgamphe (2004), poverty is deepened and perpetuated by disability, and even when children receive grants, there is economic abuse of children with disabilities when they are not able to benefit from the grants. Children with disabilities and their families should be involved in poverty alleviation programmes intended to benefit them. Services to poor children with

disabilities are not only provided by the state; community-based interventions also need to be recognised and affirmed.

Streak (2004) points out that after ten years of democracy, there is still an urgent need for the South African government to address child poverty. She proposes that the following approaches be considered in addressing child poverty:

- Programmes delivered to children should be integrated.
- There is a need for further investment in infrastructure that will increase access to services e.g. transport, roads, accessible buildings.
- Criteria for programmes directed towards children should be carefully considered to avoid the possibility of discriminatory implementation.
- Children's socio-economic rights should be synchronised with programmes that address poverty alleviation of their parents.
- Children need to be made more aware of their rights through outreach and awareness programmes.

In looking at human development in South Africa, Taylor (2000) proposed that people's perceptions of change and transformation should be examined to determine how they have engaged in the process of change. Lack of educational and employment opportunities restrict poor women's chances of creating an independent life. The 1995 South African Participatory Poverty Assessment (Taylor, 2000) reported that millions of citizens are plagued by continuous ill health, experience extraordinary levels of anxiety and stress – accompanied by the realities of violence and abuse mainly on women and children, and work for a low income. There is a pervasive sense of hopelessness because of an inability to sustain living conditions. Furthermore, Taylor (2000) found that there was a deep sense of despondency, alienation and disenchantment linked to a sense of the slow pace of change.

But the consequences of poverty go beyond mere material deprivation. Emotional vulnerability due to poverty is often not voiced or given the serious attention that it deserves. Poverty leaves people feeling vulnerable and

dependent, as their sense of security and means of survival remain tenuous. The expenditure of effort and personal resources within the domestic sphere is often seen as unpaid emotional labour that involves hard work, restrictions and a hidden labour of love, but not real work (Doyal, 1995; Read, 2000). Women who have engaged in informal care work have been a particularly powerless and hidden group, whose rights and aspirations have only been recognised in the recent past (Read, 2000). The role of the carer is seen to involve a multiplicity of skills, including handling the emotions of others, smoothing tensions between family members and providing refuge from and a counterbalance to the strains of the public sphere. Morgan (1996, in Read, 2000) extends the concept of emotional labour to disabled people who are cared for, since they have to cope with as much as the carers, but in different ways. Read (2000) found that the mothers of disabled children in Britain often experience social isolation, as the informal support network of activities available to non-disabled mothers were not necessarily *readily* available to them. She recognised that mothers from minority ethnic groups and low-income families are least likely to be members of self-help and support groups as they live on limited budgets and, therefore, are not able to buy into practical sources of help and diversion for themselves and their children.

Thus policymakers and practitioners need to understand the extent of alienation or lack of social capacity that exists in deprived communities, particularly for families where there is someone living with an impairment.

Human scale development

In considering the participation of individuals and communities in human development in South Africa, Taylor (2000) recognises that the poor may not have the same capacity as active and informed citizens or organised formations, in decision-making at every level of society. It is in this context, that the challenge for social action to change the attitudes and approaches to disability seems more daunting. Human scale development (HSD) offers a refined understanding of a people-centred development practice (Max-Neef, 1991). HSD theory considers

the fact that we live in a period of transition where paradigm shifts are necessary and indispensable to avoid the disintegration of society.

The theory of HSD identifies nine fundamental human needs, namely, subsistence, identity, protection, affection, freedom, leisure, creation, idleness and understanding. Definitions of these needs are given in Table 2.1. According to Max-Neef (1991) these fundamental human needs are universal, the same in all cultures and historical periods. Each need has a twofold character that is held in constant tension, enabling the elimination of the vicious cycle of poverty. Max-Neef (1991:24) defines the twofold character firstly as *deprivation.* Deprivation is a physiological response to an unmet need that is usually experienced as a sensation, something that appears to be missing. Secondly, a *potentiality* indicates the degree to which these human needs engage, motivate and mobilise people, and eventually become a resource. Apart from subsistence, the fundamental human needs are not seen as hierarchical, but rather each need is regarded as equally important.

Table 2.1: Definitions of fundamental human needs (TCOE, 2001)

Identity	The need to feel that you yourself are important, that you are worth something, that you have something to offer.
Affection	The sense that you are appreciated, accepted, loved; the need to have close friends or people whom you love and who love you.
Protection	The need to feel safe, secure; not scared that you are in danger.
Subsistence	The need for food, shelter, water – the things commonly referred to as "basic needs", without which a person can die.
Understanding	The need to understand what is going on around you as well as the need to be understood by others.
Creation	The need to be creative, to make things, invent things, use your own ideas and imagination.
Participation	The need to be part of what is happening, to belong to something, to take part in decisions that affect you; the need not to be isolated or ignored.
Idleness	The need to rest, reflect, relax, take time out, play, do nothing.
Freedom	The need to be free and not restricted; free to make your own choices and not have everything said and decided for you.

The diverse range of means used to meet these fundamental human needs are referred to as *satisfiers*. They are culturally determined and vary according to time, place and circumstances. Satisfiers can be seen in societal processes or practical ways or the means that people adopt or choose to structure their lives (Van Zyl, 1994). Singular satisfiers meet one need while synergistic satisfiers meet more than one need at a time. Satisfiers are seen as negative in nature, if the outcome is unhelpful or causes pathology, e.g. violence. Societal and individual pathologies occur when needs are not met or when they are met in a negative way for a long period of time (Max-Neef, 1991). Satisfiers are positive, if the satisfier leads to beneficial and constructive outcomes.

Poverty reaches to the core of a person's being and affects the human need for identity, affection, creativity and understanding of self and others (Max-Neef, 1991). Max-Neef (1991; 1995) further recognises the role of spirituality as a central dimension of being human and thus integral to satisfying human needs. The theory of HSD looks to address the problem of 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 that is not being met adequately, not just subsistence needs (Max-Neef, 1991). HSD addresses the scarcity of resources, since it views human needs as life forces that become resources to mobilise people to act to meet their needs. This approach 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).

The impact of HIV/Aids

The target group that DICAG serves is one of the most vulnerable within the HIV/Aids pandemic, consisting as it does mainly of women and children living in conditions of poverty. A literature review of *Soul City* in 2003 identified some of its impacts on children, most of which would also affect disabled children:

- People living with HIV and Aids are 36 times more likely to kill themselves than any other group in South Africa.
- According to Idasa, 14,3 million children under the age of 18 live on less than R400 a month. Of these, only 15% receive a child-support grant.
- The number of children orphaned by HIV/Aids is growing rapidly and there is no state system to deal with these orphans who are becoming more vulnerable since they tend to be cared for by poorer families with less resources. It is noted that nearly 15% of the poorest households in South Africa were estimated to be caring for orphans in 1995 versus only 5% of less poor households. (Soul City, 2003). In a recent survey about the impact of HIV/Aids on 728 Aids-affected households in South Africa, researchers reported that 11% of girls and 6,5% of boys of school-going age had either dropped out of school or had never enrolled.
- In cases where children are looking after sick adults living with HIV/Aids, the bulk of the responsibility of care fell first on the oldest girls. (Soul City, 2003)

While this review describes some of the direct impacts on children, the high rate of abuse of disabled children as cited by Philpott (2004) should also be borne in mind. To compound this state of affairs one should note that disabled children are less likely to attend schools than their able-bodied peers. However, according to (Soul City, 2003), schools are essential to AIDS prevention because they provide the best way to reach the next generation with the motivation to change behavior. Even though half of all new HIV infections are among 15 to 24 year-olds, prevalence rates are lowest among those in the 5-14 age group. This generation provides the greatest window of hope for preventing the spread of the AIDS virus.

Thus the longer disabled children are excluded access to education, the less likely they are to benefit form this strategy for HIV/Aids prevention.

The impact of HIV/Aids can also be felt as parents have their energies and, indeed, their very lives drained by the virus, incapacitating them for the arduous tasks of educating and advocating for their disabled children. The faith in the future that every advocate needs to inspire them is dissipated by the hopeless spectre of HIV.

Finally, the impact of HIV/Aids is felt with the increasing number of HIV/Aids infected and affected children who now swell the ranks of the most vulnerable and draw on the same resources as disabled children. How disability and HIV/Aids advocates can make common cause with each other in the interests of meeting the needs of orphans and vulnerable children remains to be seen. The question arises: Will they compete for resources or lobby together where there are common interests?

The impact of gender issues

Chalklen (1998) has noted that where children live in poverty, so do their families. He found that the absence of fathers in the upbringing of disabled children is of particular concern, as this worsens the poverty situation in the family and deepens the disempowerment linked to disability. The starting point for an organisation such as DICAG is one where the majority of parents are poor, female and disempowered. Within the South African context, this also means that these women are often disproportionately affected and infected by the HIV/Aids pandemic.

Speaking about the South African situation, Meer (1998) and Mda *et al.* (1996) comment that patriarchical systems serve to entrench inequalities, which keep women in inferior positions and may be exaggerated in the case of disabled women. In the political context, from the 1950s onwards, women in South Africa

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struggled against injustice and resisted apartheid, which led to the banning, imprisonment and exile of many women (Meer, 1998; Taylor and Conradie, 1997). Various studies have shown that patriarchal and cultural rituals are significant barriers to women's development generally (Abrahams, 1999; Chang *et al.,* 2003; DFID, 2000; Ramphele, 2002). Amidst the violence and personal struggles there have been victories such as the increased number of women in government at local, provincial and national level since 1994. Even before the democratic election, recognition of the role of women as mothers and wives has been high on the agenda of disability activists. The Office on the Status of Women and the Commission on Gender Equality were set up within the presidency (Meer, 1998) through the lobbying and advocacy of DPSA and DICAG.

This DICAG-NFU evaluation may be a start towards uncovering the indigenous coping mechanisms and strategies of families who have a disabled child living in impoverished contexts. The experiences of organisations such as DICAG have been underrepresented in many studies on poverty and development, thus leading to the exclusion of disabled children and their parents from mainstream research and policy development. The vicious cycles of dependency, isolation and poverty are very hard to overcome when few resources are available. It is imperative that ways are found to correct such inequity.

Advocacy and service delivery

With the advent of democracy in South Africa and the subsequent policy development, a space opened up for advocacy where previously there had only been struggle and resistance. The typical NGO which had engaged in provision of alternative services and support of resistance to apartheid now found dwindling funds for service provision which the democratic state was now expected to provide. The NGO role became one of monitoring and advocacy. However, time has shown this to be a simplistic point of view. The process of policy implementation and service delivery has proved to be much more complex

and long term than the initial optimistic expectations of democracy. The crucial question is: How, in this situation, does any organisation maintain its credibility if it avoids service provision to address the immediate unmet needs of its constituency? It is precisely this dilemma that DICAG finds itself caught up in. This tension is not easily resolved where there is a lack of service delivery by the state.

Implementing community-based rehabilitation

In the face of the difficulties described above, there should not be a reaction of doom and gloom as there are many positive developments that make an impact on the lives of disabled children and their families. Approaches to CBR have been diverse within community development, because it is more than a service – it is about 'how' the needs of disabled people are met, rather than 'what' is done (Hartley 2002; Price and Kuiper, 2000; Thomas and Thomas, 2000). One of the common weaknesses of CBR programmes in Africa is that they have been initiated and supported by NGOs and DPOs on a small scale with limited involvement from government (Finkelflugel, 2004; Hartley, 2002; Haricharan and Rendal-Mkosi, 2004). Since its inception, CBR has been an approach that has focused on delivery of rehabilitation services in poor countries. It has been implemented in contexts which are diverse, complex, dynamic and uncontrollable, with professionals who are generalists, and more likely to be women (Thomas and Thomas, 2002; Wirz, 2000). The literature calls for clarification on the roles of stakeholders in CBR and the relationships between these roles. Common stakeholders who have been recognised include the disabled, their family and community, as well as community rehabilitation workers, volunteers, and professionals who work for NGOs or different government services (Asindua, 2002; Coleridge, 1993; Finkelflugel, 2004; Hartley *et al.,* 2002). DPOs feel strongly that disabled people are not merely recipients of CBR, but contribute to its sustainability, as the skills, philosophy and attitude remain behind when external facilitators leave (Ndaziboneye, 2002).

Many of the changes in understanding disability can be attributed to the growth of the Disability Rights Movement internationally (Charlton, 1998; Finkelstein, 1993), as well as the development of Disability Studies programmes internationally (Barnes and Mercer, 2004; Lorenzo *et al.*, in press). Oliver (1990) was instrumental in developing the social model of disability, which called for a shift in paradigm from seeing disability as a tragedy and individual issue, to seeing it as a social and political issue. The social model of disability proposed by the Disability Rights Movement does not place the onus for inclusion on the disabled person as an individual, but rather on changes at a societal level. The Movement maintains that equalising opportunities would result in substantial changes in the social, economic, cultural and political spheres of life, instead of the present focus on medical rehabilitation in CBR programmes (Cilliers, 2004; Cockburn, 2003). A focus on equal opportunities in CBR would reinforce disability as a political crosscutting issue that becomes the responsibility of civil society, public and private sectors and all ministries of government (ODP, 1997; WHO, 2003). Such an approach promotes the full social inclusion of many other marginalised and oppressed groups, and contribute to poverty alleviation strategies. With the growth of the Disability Movement, there has been a call for partnerships with professionals whose role would be as a resource, to share their knowledge and skills as determined by DPOs and families of disabled people. In tackling human development, CBR and disability programmes are challenged to identify relevant indicators of empowerment and social change as related to *Rule 20* on Monitoring and Evaluation in the UN 22 Standard Rules on the Equalisation of opportunities for persons with disabilities (UN, 1994). The Rules are divided into three sections. The first four focus on the preconditions for participation; the next eight rules look at the target areas for participation; and the last ten rules describe implementation measures.

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SECTION 3

METHODOLOGY

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Introduction

The evaluation team used a naturalistic qualitative research approach that allowed for a flexible yet in-depth inquiry. This approach facilitated engagement and active involvement of DICAG members in the evaluation process, so that they would not become the objects of evaluation, but to all intents and purposes, would find mutual learning and benefit from participation in the process.

The methodology was descriptive and used both qualitative and quantitative methods. Bailey (1997) commented that qualitative data were rich and powerful with the potential for revealing complexity. This resonated with the purpose of this study, since the factors that impact on the development of people are complex.

Target group

Given the huge disparities in resources throughout South Africa, it was proposed that the evaluation be conducted in both a rural and urban setting. Therefore, the Western Cape (relatively well-resourced), as well as the Eastern Cape (far less resourced) were selected as sites for the evaluation. It was envisaged that this would allow for the development of recommendations that are relevant to diverse settings and that it would ensure greater applicability to the rest of the country.

Data generation

There were four methods of data generation, namely:
1. Document review;
2. Key informant interviews;

3. In-depth interviews; and
4. Focus group discussions.Focus group discussions

The interview schedule was derived from the TOR, outcomes of the document analysis and Kaplan's (1999) organisational capacity theory that identifies the six features of organisational life: conceptual framework; organisational attitude (culture); vision and strategy; structures and procedures; individual skills, abilities and competencies; and material resources. This framework was combined with Kaplan's (1996) phases of organisational development, namely, dependence, independence and interdependence. The tool used in the focus group discussions was based on the Wheel of Opportunities developed by Lorenzo and Sait (2000) as a participatory evaluation tool that identifies the UN 22 Standard Rules for the Equalisation of Opportunities.

Data analysis

A descriptive analysis was done to provide quantitative data. It should be noted that the outcomes of analysis cannot be seen as completely accurate because some of the evidence was only received after the preliminary report had been submitted.

Analysis of documents

The qualitative analysis was done deductively using Kaplan's framework for organisational capacity (Kaplan, 1999). The Centre for Development Practice – formerly known as the Community Development Resource Agency (CDRA) – maintains that the elements outlined in Figure 3.1 need to be present and coherent for an organisation to have capacity and to be effective (Kaplan, 1999). In Figure 3.1 these elements are arranged in a hierarchy of importance with the top three elements being transitory and invisible but determining the capacity of an organisation and its seen effectiveness; and the lower three elements being visible and tangible and more easily measurable.
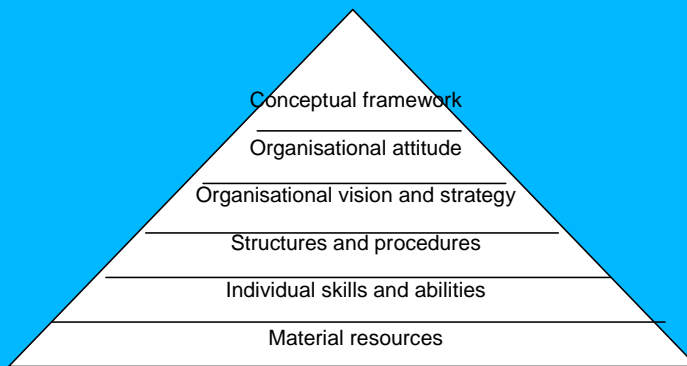
Figure 3.1: Elements of organisational capacity[5]

Kaplan's framework for organisational capacity is explained as follows:

- The *conceptual framework* reflects the organisation's understanding of the world.
- The *organisational attitude* incorporates the confidence to act in and on the world in a way that the organisation believes to be effective and to have an impact, while accepting responsibility for social and physical conditions 'out there'.
- The *organisational vision and strategy* provides a sense of purpose and flows out of the understanding and responsibility of the organisational attitude.
- *Organisational structures and procedures* are defined and differentiated to reflect and support vision and strategy.
- *Individual skills, abilities and competencies* are relevant to the task at hand.
- Material resources should be sufficient and appropriate.

Analysis of interviews and focus group discussions

Themes emerged from an inductive analysis of the interview and focus group transcripts regarding the impact of the DICAG-NFU partnership on the development DICAG as an organisation. These themes were confirmed through

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[5] Kaplan, A. (1999). *The development of capacity*. UN non-governmental liaison service (NGLS): Switzerland and New York.

consultative dialogues that the team members held on a weekly basis for the period of evaluation so as to deduce whether there was congruence with Kaplan's (1999) six elements of organisational capacity that were used as a framework for the document review (see Section Four). Categories were also identified that have a direct impact on any given theme. Although themes are presented individually, the reader should bear in mind that there are interconnections as one theme influences and relates to the others.

SECTION 4

FINDINGS OF DOCUMENT REVIEW

Introduction

The terms of reference (TOR) for this evaluation focused on the approach to organisational development that has been implemented. The evaluation will take cognizance of the recommendations of the previous two evaluations. In this regard, the tensions related to the role of DICAG in advocacy and development activities will seek to explore whether delivery of services becomes a strategy for advocacy, using an action learning and participatory development approach.

From early on in the DICAG-NFU partnership, it is evident that there was a tension between whether to focus on advocacy or on development related to service delivery (Philpott and McLaren, 1999). Three objectives were identified:

1. Advocacy activities;

2. Development activities; and

3. Partnerships.

Hertzberg and Comninos (2001) found that an overall strategic plan for the organsiation was absent, as well as a clear definition of the roles of all the stakeholders. They saw DICAG moving from an activist organisation to a DPO. Their recommendations include:

1. Do an organisational review of DICAG as a first step in a participatory development process. The review should consider membership, political structure and staffing in relation to DICAG's objectives.

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2. Do a national strategic plan to be approved by national congress and executive. The plan should set targets for advocacy, parent empowerment and organisational development (structure, roles and responsibilities).
3. The national plan should include training strategies within three targeted areas:
   - Advocacy;
   - Empowerment of parents, youth and children; and
   - Organisation development of the membership organisation.
4. A plan of action should be made for each province, based on the national plan developed.
5. An appropriate model of project cycle management should be used as a basis for all plans developed so that adequate monitoring and evaluation is facilitated at every level in the organisation.
6. The training needs of the organisation should include:
   - high level capacity building of office bearers and staff (planning, management, financial, etc.); and
   - general capacity building of members (organising themselves, lobbying, early childhood development, their rights etc.).

There seems to be a contradiction with our TOR as Philpott and McLaren (1999) recommended that the focus shift from parents to children! We have remained with the TOR for this evaluation. The documents that were made available for review are listed in the appendix. We only received the visit reports for 2003 and 2004 in December, thus these reports were not included fully in this analysis. The descriptive data presented have been compiled with a view to giving objective evidence about the nature of the relationship between DICAG and NFU. Much of the information is subject to interpretation and therefore difficult to present in summary or numeric form.

The findings of the document review are presented using Kaplan's (1999) six elements of organisational development.

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1. Conceptual framework

Reflects the organisation's understanding of the world (Kaplan 1999)

The mission statement describes DICAG as an independent, national non-government, non-racial parent organisation of disabled children and their parents. DICAG's mission reflects that this will be done through the parents. DICAG put emphasis on issues of social justice, the protection of human rights and development opportunities for people with disabilities (PWDs) within the context of the African Decade of Disabled People. The new found South African democracy was recognised as a fragile situation that needs to be sustained by civil society so as to develop policies to address the inequities of the past, particularly the consequences of poverty. NFU made the agreement that it will contribute to the development of DICAG into a powerful, democratic membership- based, national advocacy organisation of and for children and young adults with disabilities in South Africa.

There has been a shift in national resources from the (white) minority to the (black) majority. And yet there are still many challenges facing the country, challenges left by the legacy of racial oppression. The major threat to children with disabilities and their families is no longer that of racial discrimination, but that of poverty. (Philpott and McLaren, 1999:1)

2. An organisational "attitude"

Incorporates the confidence to act in and on the world in a way that the organisation believes can be effective and have an impact, and an acceptance of the responsibility for social and physical conditions "out there". Organisational attitude includes an understanding of the context and responding appropriately to that context (includes sufficient information). (Kaplan, 1999)

DICAG came to the realisation that advocacy would achieve real benefits in the long term. In the meantime parents were concerned about immediate needs and thus a parallel focus became development activities that would address poverty

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and exclusion. It seems that the differences in cultural and social contexts of disability between South Africa and Norway were not clearly communicated or understood related to the purpose of the day care centres. These different frames of reference led to tensions in understanding the roles of day care centres and advocacy. NFU appears to see them as separate functions and DICAG sees them as activities occurring simultaneously. NFU is underpinned by a belief that prefers government to take responsibility for services of PWD's. Thus NFU perceived that DICAG had shifted from the initial agreements.

> *The question remains, however, as to whether it should be DICAG's role to act as a service provider or whether, truer to its original aims it should advocate for others to provide these services.*

The document analysis also revealed the nature of the organisational culture. There was a high turnover of staff in DICAG and NFU that could contribute to lack of confidence, competence and capacity.

3. Organisational vision and strategy
Clear and provides a sense of purpose and will, which flows out of the understanding and responsibility of the organisational attitude (Kapland, 1999)

The purpose of the 1999 evaluation (Philpott and McLaren, 1999) was specifically to inform strategic planning for the period 2000–2005. Their strategy was advocacy to raise awareness on disability issues to benefit disabled children who are marginalised. The vision and strategy of DICAG as a DPO has been focused on building capacity of local parent branches to engage in partnerships with the public and private sector as well as professionals.

An analysis of the membership of the organisation (See Figure 4.1) showed that DICAG started with a very high membership in 1999 (over 3 000 members) that dropped radically in June 2000 and in 2001. The upswing started in 2002 and there has been consistent growth since then, to the highest point in 2005 of over 3 500 members. However, it is not clear to what extent there is individual or

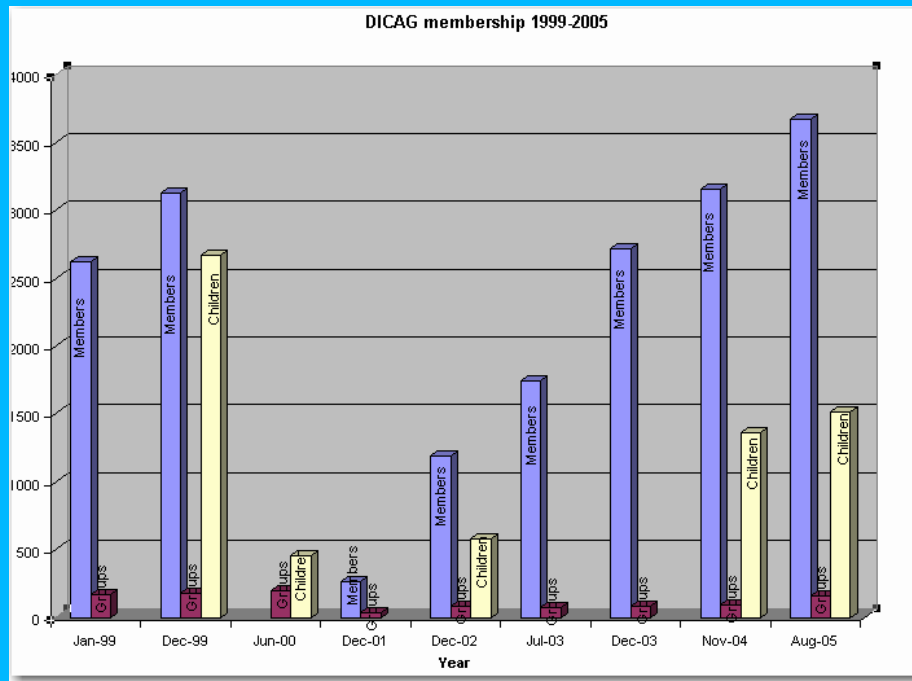group membership from year to year. For example, the figures for 2000 do not show any individual members.

DICAG membership 1999-2005

| | Jan-99 | Dec-99 | Jun-00 | Dec-01 | Dec-02 | Jul-03 | Dec-03 | Nov-04 | Aug-05 |

Figure displaying Members, Groups, and Children bars by year (Year on x-axis, values 0 to 4000 on y-axis).

Figure 4.1: DICAG membership 1999–2005

The reports from which these figures are drawn also make it clear that membership in the early days could have been unreported due to lack of administrative capacity to record and monitor membership. However, it is interesting and encouraging to note the strong upswing of membership during the period of NFU funding, especially since this funding is specifically directed towards the development of DICAG into a powerful, democratic membership based, national advocacy organisation. It is not clear whether groups are affiliates, or local parent branches of day care centres.

The database for 2005 seems to be comprehensive and is analysed by province (see Figure 4.2). The distribution of membership across the provinces indicates

that DICAG is clearly a national organisation, with the Eastern Cape, North West Province and Mpumalanga having the strongest membership in terms of numbers. However, this needs to be seen relative to the population of these provinces. Northern Cape as a sparsely populated province has the lowest representation, but Gauteng is surprisingly low, as is KwaZulu-Natal.
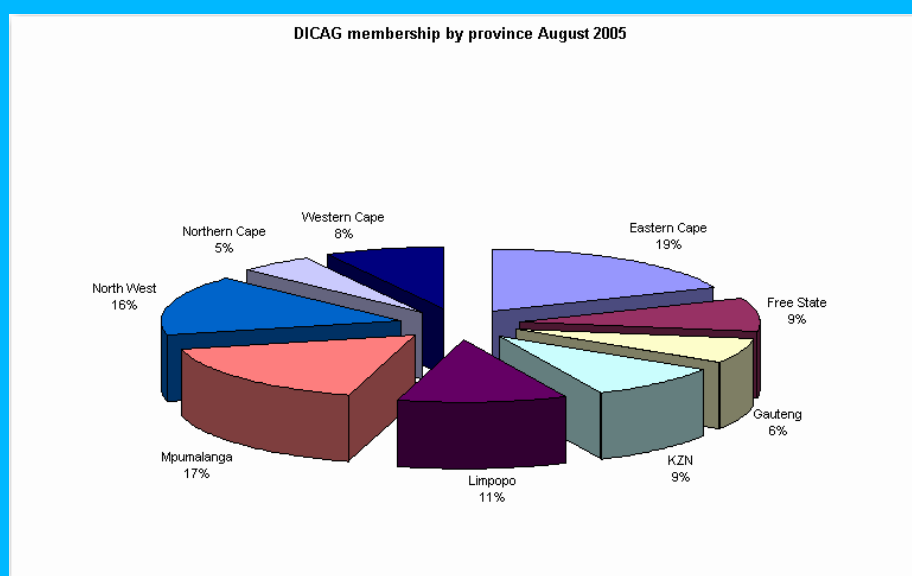

Figure 4.2: DICAG membership by province as of August 2005

As mentioned earlier, a parallel focus on development was seen as essential, and day care centres had potential as a tangible and ongoing strategy for advocacy and development. In this way, DICAG had a vehicle to build the skills of parents as advocates. DICAG has recognised the need to develop strategies to engage government in sustaining 30 day care centres.

In this regard, DICAG has recognised the strategic partnerships with the national and provincial offices of the Office on the Status of Disabled People. Another strategy that was explored for a short period of time was a partnership with the academic sector for university student placements that would develop parent

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potential and teacher training so that confidence to integrate and manage disability issues was sufficiently enhanced.

Media were another vehicle for disability awareness and advocacy. Overall, information as a strategy to prompt action for transformation has been identified as a key strategy.

4. Organisational structures and procedures
Defined and differentiated to reflect and support vision and strategy (Kaplan, 1999)

DICAG had established provincial structures in eight of the nine provinces by 1999. The constitution outlines communication lines and there is the impression that national and provincial structures are co-ordinated. But there seems to be a problem establishing the structures of the local branches. The challenge appears to be a difficulty in developing a logical framework and operational plan that filters down to local branches.

There was also an urgent need to address the role confusion and conflict of responsibilities between DPSA and DICAG at provincial and national levels. Tensions, divided loyalties and confusion occurred when DICAG separated from DPSA, especially at a provincial level, where DICAG set up provincial offices in collaboration with DPSA and other NGOs. Philpott and McLaren (1999) identified the apparent tensions between DICAG and service providers. In the evaluation of DICAG, Hertzberg and Comninos (2001) found that there was still a need to develop a new organisational structure that would enable DICAG to develop its own identity.

Staff consists of a national co-ordinator (administrator/CEO), which was vacant for a period around 2000. Advocacy and development co-ordinators were also appointed during the period of the partnership. Roles and responsibilities reflect a need for clarification between different committees: national council, national

executive committee, provincial development team meetings; provincial executive committee, local branches. National Council and provincial development committees are elected every five years. The role of the office bearers and the employed staff is not clear. Job descriptions are not clear.

Difficulties were identified related to the understanding and administration of membership. Though the constitution clearly defined the membership criteria, it appears that the issues were not discussed clearly. This became a bone of contention later as parents did not see themselves as members of DICAG, which started as an advocacy organisation. Later on, membership mainly consisted of affiliated groups (local branches), but there was also flexibility for individuals who only had a remote relationship with DICAG.

The documents clearly reflect that DICAG was active in creating alliances around specific issues e.g. child abuse, barriers in the workplace to maximise publicity campaigns. Advocacy activities included policy development, children's rights campaign and changing attitudes, which involved partnerships between different national and provincial government departments and non-governmental organisations. The Centre Upgrade Programme (CUP) was recognised as an effective strategy in this regard. Development activities included organisational governance, training of the provincial development teams, parent empowerment and child development.

The national office of DICAG developed a newsletter to facilitate communication with members of organisation and to impart topical information. Such action showed an intended congruence between the organisation's vision and strategy and the structures and procedures that were put in place to put effect to the vision. While there was recognition that dissemination of information was vital, communication systems were unclear and there was inadequate organisational support to carry out roles.

An information system was initiated in1999. This system has potential as advocacy tool. From Philpott and McLaren's (1999) evaluation report, the following indicators for organisational governance can be deduced:

1. Access to information;
2. Availability of records of what has been done (e.g. minutes and reports) enabling accountability;
3. Contact details of day care centres and partners; and
4. Clear goals, objectives and a programme of action as monitoring tools. This would operationalise the vision and mission of DICAG at provincial level.

5. Individual skills, abilities and competencies
Identify the relevant skills and competencies needed (Kaplan, 1999)

Documents showed that most advocacy work appears to be conducted at national and provincial level. It was difficult to see the impact of advocacy training at local branches, as local group members appear relatively ill-equipped to carry out advocacy themselves. In addition, DICAG's objectives are not clearly understood at a local level. It was evident that pressure to provide support to day care centres had gradually built up. Documents identified the need to focus on capacity development to build the competence of parents related to their knowledge of their child's rights, laws and lobbying skills: being parent does not equal the qualification to be a manager. There was also a need to balance the delegation of roles and responsibilities. An analysis of recommendations from NFU visits 2000–2004 suggest that NFU's main concerns seem to be with the relationship between the administration and the membership, and the connections between the national, provincial and local branch levels. The frustration seems to be directed at these issues rather than a conflict between development activities related to advocacy and skills development of children and parents. The details of recommendations from each visit report can be found in Appendix 4.

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Philpott and McLaren (1999) found that the sustainability of the organisation would depend on capacity building of executive committees in leadership, project and financial management. Clarke (2004) raised the issue of capacity utilisation. The strengthening of provincial leadership and development of sustainable structures necessitated:

1. Building confidence of parents to engage professionals or service providers on an equal level;
2. Infrastructure development with resources for communication and record keeping so as to improve co-ordination and communication of activities in the provinces; and
3. Logistical support for the provincial co-ordinators.

The training activities have been divided up into two different categories (see Table 4.1), according to previous recommendations from evaluations. While this division might not be a completely accurate reflection, it does indicate that there has been extensive training of both types conducted within the organisation. However, the evidence shows that there was little consistency of training from one year to the next and there does not seem to be an overall plan. Neither do the reports indicate the number of people trained. The link between training activities, advocacy and organisational development needs to be more clearly defined. It is possible that a training audit should be done and follow-up mechanisms set in place including mentoring and on-the-job coaching.

Table 1: Training activities undertaken from 1999–2004

High level capacity building of national and provincial office bearers and staff	General capacity building of members
• Leadership development • Financial management • Networking skills • Capacity building • PDT meeting • Portfolio management • Funding proposals • Business plan development • Masters in Disability Studies at UCT • Developmental disability – Cape Mental Health • Presentation skills and workshop design • Advanced computer literacy • Reception management • Communication and liaison • Diploma in Auditing and Accounting • Diploma in Education, Training and Development • Employment Equity and labour relations • Strategic planning • Business plan development • Inclusive ECD practices	• Standard rules • Handling the child • Parent mobilisation • Parent empowerment • Attitude and awareness • ECD practices • Respite care • SA Law commission on Child • Care Act • Rights of the child • INDS • Advocacy • Youngster life-skills and capacity building seminars • HIV/Aids and stigma • Child abuse • Local parents branches • Constitution writing • Centre management • The relationship between the disabled child and the family

6. Material resources

Need to be sufficient and appropriate (Kaplan, 1999)

An analysis of the budget allocation of NFU funding shown in Figure 4.3 is drawn from DICAG financial reports from 1999–2003 and reflects the expenditure of funding from NFU. These line items covering the different activities have been divided into categories as follows for the purpose of analysis:

1. Total advocacy: Provincial advocacy, policy development, children's rights campaigns, materials development, training and advocacy;

2. Total resources: PMRG books, resource mobilisation;

3. Total governance: Provincial leadership, governance development, membership development;

4. Total specified training: Attitude and awareness training, parents professional workshop, inclusion workshop, legal literacy, parent empowerment;

5. Total networking: International networking, NFU visit to SA, NFU Norway conference; and

6. Total salaries and administration: Programme personnel, salaries, administrative costs, audit and accounting fee.

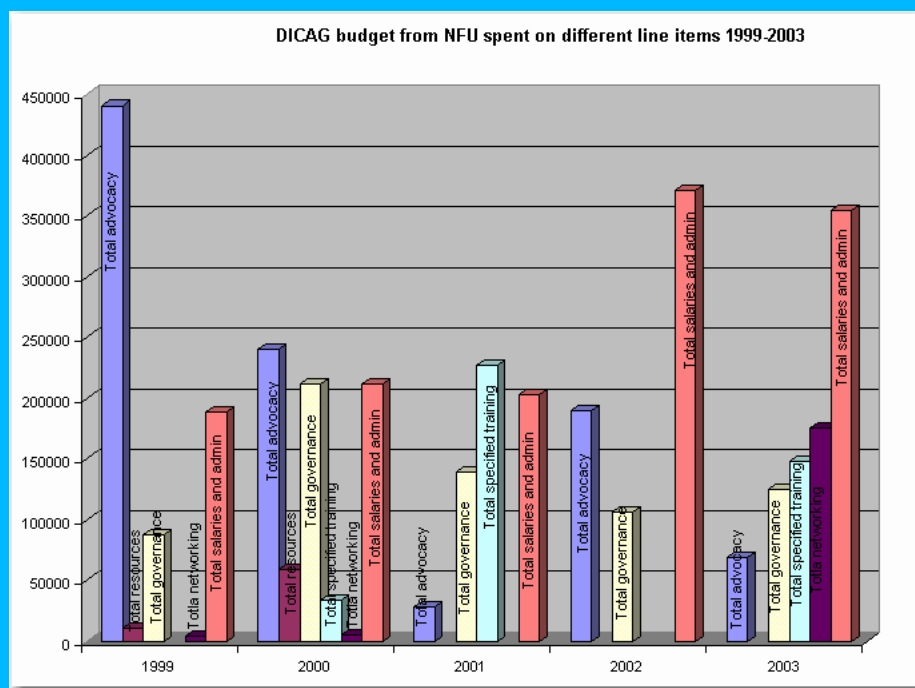(See appendix for graphs of each of these aspects).

Figure 4.3: DICAG budget from NFU spent on different line items 1999–2003

The indication is that while funding for advocacy was greatest in 1999, the funding later shifted to salaries. This meant that there was less money for advocacy activities at local branch level. In line with the NFU agreement, there

was very little spent on resources for infrastructural development that would support advocacy activities. The pie chart in Figure 4.4 shows that 61% of the budget was used for networking, advocacy and training in line with NFU requirements.
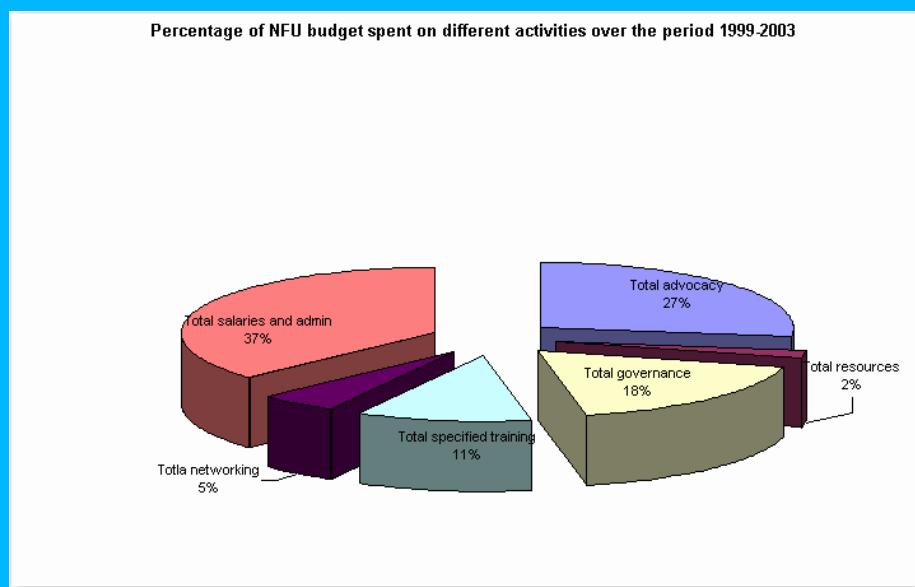
Percentage of NFU budget spent on different activities over the period 1999-2003

Total salaries and admin
37%

Total advocacy
27%

Total governance
18%

Total resources
2%

Total specified training
11%

Totla networking
5%

Figure 4.4: Percentage of NFU budget spent on different activities over the period 1999–2003

Advocacy materials that were developed included:
1. Disability Etiquette and Welcoming Disabled Customers booklets for various government departments
2. Pamphlet: "Mobilising for a Caring Society", Department of Welfare
3. Pamphlet: "You and Social Grants 2000", Department of Social Development
4. Pamphlet: "Population & Development in the New Millennium", Department of Welfare
5. Department of Welfare – Annual Report 1998/9

6. HIV/AIDS & STD Strategic Plan for South Africa, 2000–2005, Department of Health
7. The Welcome Book – A guide to help teachers include children with disabilities into the classroom, Early Learning Resource Unit, 1998

The documents revealed that accessing resources to support day care centres was an obvious area requiring sustained advocacy, as substantial upgrading was needed before registration would be considered, and even then a subsidy from the Department of Social Development was not guaranteed. R4 000 was received by DICAG to purchase equipment and apparatus for day care centres.

DICAG aimed to carry out one major fund raising event every year. Other than this, there was no clear strategy regarding fund raising. Concerns were raised regarding funding beyond 2001 when the NFU contract expired. There was lobbying to resolve this situation and to ensure that Norwegian disability organisations are able to continue their international solidarity development beyond 2001. In the future three–year contracts for funding would be considered.

SECTION 5

FINDINGS FROM INTERVIEWS AND FOCUS GROUP DISCUSSIONS

Introduction

In the wake of the first democratic elections in South Africa, DPSA was instrumental in placing disability on the political agenda more so then at any other time. As a result, DICAG was able to develop fully and with advocacy activities implemented via day care centres. This was prior to NFU's involvement. The challenge of developing capacity in an NGO such as DICAG calls for an approach that is not rigid and cold. This section presents the seven themes (see Figure 5.1) that emerged from the interviews with participants who have been involved with DICAG during the period of the NFU-partnership. Although the interviews were conducted at the present time, the reader needs to take into cognizance that some statements from respondents depict different time frames. Discussion is integrated within each theme.

Figure 5.1: Summary of themes

1. The complexities of poverty

Poverty emerged as a significant challenge to organisational capacity as it undermined access to resources, which led to the breakdown of trust between the different role players in the partnership, i.e. the leadership, the staff, the members and the funder. It was also evident that there were different interpretations of poverty.

2. Bottle-necking of information networks hampers organisational ownership

Information dissemination was seen as an essential tool for advocacy and the development of local branches. Communication was identified as a major stumbling block towards fostering ownership of LPB's initiatives due to the vastness of South Africa. No finances at LBL hindered information dissemination. However, there were limited financial resources available.

3. An organisation in a state of vulnerability

There were two responses to DICAG's state of vulnerability: on the one had a state of panic that resulted in energy to act; on the other hand, a state of despair that led to blaming between the leadership, staff and local branches.

4. Pride in DICAG's achievement

When DICAG members stay true to their values, there is satisfaction and growth at different levels. DICAG had been able to gain recognition from local through to international arenas. Members grew in confidence through mutual sharing and exchanges as a strategy for horizontal learning.

5. Tensions related to diversity issues

DICAG as an organisation mirrors the tensions related to issues of diversity, namely, gender, race, politics and class.

6. Excited and confused leadership

It was evident that DICAG membership and funders experienced a range of emotions in developing the structures of the organisation at different levels as roles and responsibilities had to be continually visited. Such emotions seemed to be linked to degrees of ownership of the process by the members. Effective communication systems are essential.

7. Conflict in funding strategies for enhancing people-centred development

While NFU suggested the development of local branches there appeared to be insufficient infrastructure and resources committed to run the local Parent branches. NFU consultants might have been more costly than using local consultants.

1. The complexities of poverty

Kaplan (1999) maintains that there are many forms of poverty, economic poverty being only one of these. Max-Neef found that poverty occurred if any one or more ~~o~~if the nine fundamental needs were not satisfied. Parents of children with disabilities are recognised as a vulnerable group as they are undermined and excluded within their own communities (ODP, 1997). Most of these parents are single mothers with the fathers having left after the birth of a disabled child. The perception is that their experience is one of internalised struggle and oppression that can result in various types of negative approaches to situations.

Moreover, the interviews uncover a perception that day care centres were seen as a synergistic satisfier of the parents' human needs for identity, creation and freedom and for the human needs of subsistence, understanding and participation as they gave access to resources, including jobs. Day care centres also satisfied the human need for identity of disabled children, as they were no longer hidden in their own homes. Mothers had some respite from caring, thus meeting the human need for idleness or rest. One parent mentioned that DICAG gave her a sense of belonging (the human need for affection), whereas others felt that it was about meeting the human needs of identity and protection for their children. Apartheid left many people lagging behind in the development of various sectors, especially in the rural areas. There are severe backlogs regarding the needs of disabled people. What would be interesting to know is how the membership of DICAG understands the complexities of poverty. Some of the membership saw the lack of funds as hindering organisational development, while others saw poverty as being a bigger issue than just money. The question arising from this evaluation would be: How much did DICAG and NFU contribute towards the membership gaining an understanding of themselves in order that they are better able to take control of their own future? An indication of how this was addressed would lie in their ability to find effective solutions to questions, problems and concerns, including economic and political

marginalisation.

2. ~~Information as a vehicle for empowerment~~**Bottle-necking of information networks hampers organisational ownership**~~Information dissemination was seen as one of DICAG's primary activity. Some participants saw access to information as a tool for empowerment of both disabled children, their parents. There was potential for local parent branches to act as a vehicle to facilitate access to information. I think the most important or fundamental aspect that DICAG would focus on is giving parents that access to information. … The first thing would be to set that person up with the closest local parent branch in the area. But also to forward relevant information about the child's disability…There is no information for those branches and support groups that we have established and the purpose of establishing ama -support groups or ama-branches was to make sure that you know parents came together and share the experience and as they are waiting well…~~

The prevailing situation of funding constraints was seen as a hindrance to information and organisational development, as information did not flow from national level through to the PEC and then to the local branches. In the same way, information did not seem to work upward either. The loss of financial resources threatened the loss trust in DICAG as an organisation. However, there was a risk that dependency on outside sources of funding (either from the national office to local parent branches or from funders) was created. Hence the comment:

> *DICAG has established ama-branches and we are not getting anything, we are not getting i-training and we are not empowered, you know, the way- may be the way we expected or the way we were told: so it is going to happen to our branches. S the people they will lose i-trust …*

The question needs to be asked: What capacity was built if the organisation is dependent on external funding for the branches to operate? There was no clarity on whether the development of local parent branches was budgeted for or not.

Comment [Bettina T1]: I don't know what this means.

Some participants challenged the way membership handles information. There was a perception that stories regarding DICAG as an organisation for parents and children with disabilities were being lost. Therefore, a way to capture the stories people tell each other about the ethos of the organisation would be a valuable resource for other organisations to learn from. These stories may further assist in the development of partnerships, an essential component to development of capacity within and outside the organisation.

Communication was identified as a major stumbling block to fostering ownership of the local parent branch initiative because of the vastness of the country. Access to the Internet was difficult as people rely on cell phones instead of landlines. Parents of children living with disabilities need to be capacitated in understanding democracy. There was also a perception that new members of the organisation often did not understand or have knowledge of the history of how the organisation had developed. The tendency to protect one's turf was seen as a challenge at local parent branch and provincial level. Staff turnover meant that new staff had to familiarise themselves with operations. There was a feeling that members were influenced by the marketing skills of NFU consultants without understanding the implications of proposed strategies. Tensions were evident at PEC level, as members did not voice their unhappiness with situation of *"being in the dark"* especially about financial matters. Thus drying up of funds impacted negatively on the functioning of the PECs or local parent branches:

> *NFU said to DICAG you have to establish ama-branches so that information can go straight. [So] we did that. We have established those branches, others are existing. Others, others are no longer existing … Now the funder is pulling out … because we have established [the branches]. We did what the funder want and all of a sudden the funder is pulling out. And it really frustrates, you know, i-staff and it really frustrates the members kwi-DICAG.*

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Comment [Bettina T2]: So NFU needs to become better at communicating and explaining the whole agenda and background of selected strategies for organizational development?

3. An organisation in a state of vulnerability

One would assume that members who have access to information regarding the status of their organisation would act from a position of knowledge, which is a position of strength. Yet surprisingly enough, it was the local parent branches that challenged their leadership about how they were doing things. There was an emerging sense of loss of trust. In some areas, the leadership appeared to be distancing themselves and speaking as if they were outsiders, thus creating a missed opportunity for a constructive dialogue.

A state of vulnerability seemed to exist as members felt that "*even though we did what they wanted"* the funders were "*pulling out".* Such comments reveal an absence of ownership of the concept of local parent branches as a way of strengthening and sustaining the organisation.

The evaluators noticed a cycle that was emerging regarding the present situation in DICAG. The membership appeared to feel vulnerable with the lack of funds and there appeared to be two responses to the situation. On the one hand, local parent branches and PECs were galvanised into a state of panic, which energised them to take action. This energised state led to connecting with partnerships and alliances to assist the organisation to restrategise. On the other hand, the vulnerability led to a state of despair resulting in frustration, which often caused a cycle of blaming between the leadership and the branches. Members seemed to be paralysed into waiting for something to happen: such dependency on funders led to passitivity and learnt helplessness. In a crisis members were unsure of how to reorganise and advocate for the present situation. What further compounded the state of vulnerability for members of DICAG was a lack of strategy to guide the organisation during this difficult time. This might be related to the lack of clear norms and procedures regarding the selection of leadership, including general staff recruitment.

Power relations between DICAG and the funding organisation impacted on DICAG's ability to forge an equal partnership. Differences in the partnership were not recognised and brought into the open and so left DICAG in a state of vulnerability. Therefore, before a model of practice is adopted from another context, it needs to be thoroughly debated for its impact on the local context. This impact led to comments like:

> *Norwegians, yha they have their own culture, you know. Sometimes you find that they want us to practise what they are doing in Norway … when it comes to South Africa it won't be like that … You don't have to argue. Those are some of things which leads to the development … some of their things gave us a success but other things we cannot do because our culture and Norwegians' i-culture is something else. So those are some of the arguments we normally have with them.*

4. Pride in DICAG's achievement

It became apparent that the members had a sense of pride in the achievements of DICAG as their organisation:

> *The move from DPSA to an independent organisation with our own programmes was a good move because ... we have raised funds which are more focusing on children and parents. While we were with DPSA, you know the focus was on other issues and you may find out that when funds come then children are getting you know small amount …*

> *There will always be a very pronounced sense of pride to be affiliated to an organisation that has taken us as a project first, and then seen to it that we evolved to an organisation that is internationally recognised. And I think it a wonderful thing that we could come out as a small parent organisation … We are recognised from the shores of Jamaica right across to the East.*

Thus the members felt that they have reaped the fruits of their hard labour and some identified consistency, patience and compassion as the key to their success. It was evident that when DICAG members held true to their values, there was satisfaction and growth at different levels. There was growth in sharing and through sharing the members learnt from each other. Also, empowerment was seen as an enabler because it was when capacity was built, that DICAG members were able to take up opportunities available to them. The empowerment of parents produced role models. For example, one parent told of moving from starting a day care centre in her community to being nominated as a Community Builder of the Year in the Western Cape. This parent had managed to mobilise resources to build ten safety homes catering for both disabled and non-disabled children in her community.

The findings show that as DICAG members grew in confidence they were able to work on strategies that would further promote growth and development of DICAG as an organisation. Parents were empowered to such an extent that they were able to initiate partnerships with government at various levels. Therefore, partnerships were seen as an essential strategy that would assist DICAG to

articulate and lobby for service provision and integration of issues of childhood disability. Through local parent branches, local municipalities are taking note that children need access. Both North West Province and Mpumalanga Province are very good examples ~~of meetings,~~ where no govern~~or a~~rment meetings~~committee~~ happen without DICAG's participation, or where provincial government does not have any activity without the presence of DICAG. Northern Cape was the last province where parents were mobilised. They have an office within what we call a One-stop area (a service point where needs of disabled people are attended to), which is an initiative of provincial government. Advocacy campaigns have also fostered the growth of DICAG membership as is evident in the growth of the local parent branch in a rural area in the Eastern Cape:

> *Today we have developed a parent power movement, the membership booklet. The members that are joining the organisation are from areas that I was not even aware was on our map. Ntabankulu!! We had a birth certificate campaign in Ntabankulu that was, you know- we managed to register over 80 children that did not have IDs in that area. Disabled children in Ntabankulu and because of that we've got over 80 members on our database.*

At a continental level, there are new organisations that are starting in other countries such as Namibia. A very new organisation that is struggling just to get their government to understand that disability is an issue has called upon DICAG to help in terms of how did DICAG does it with its advocacy campaign.

Growth in the development of DICAG members occurred more successfully when culturally competent consultants were used continuously, as the language was accessible and cultural differences are taken note of prior to the workshops:

> *There was an ability to have direct dialogue with people, you know, people are more comfortable. And workshops have been fun and that gained much more … Lots more knowledge, lots of empowerment, people are able to really stand up, you know.*

Capacity and growth are developed through sharing between local parent branches and beyond. A sense of appreciation to those who support the growth of DICAG was evident:

> Parents formed their own garden project from the land that we got from the municipality … NFU has helped a lot because of their input related to the concept of inclusion. Now we work hand in hand with the schools. They taught us advocacy and how to combine disabled and non-disabled children. When we have some meetings and awareness days all the teachers attend them.

A significant change over the years that DICAG fought for as an advocacy organisation within the disability movement is for policies and laws that would protect their children. Support for implementation of these policies is now needed from different stakeholders, including funders.

5. Tensions related to diversity issues ~~Embracing issues of difference and diversity~~ ~~*If working with nine provinces and coming from your own cultural identity its important that you relate to other people, that its not just about relating, it about understanding, its about having that respect for people who have other cultural practices. But its also a two way process… Everybody had run a series of workshops with them as part of that we dealt with cultural diversity, and that is the starting process*~~

The struggle for the majority of children with disabilities and their parents from diverse backgrounds is varied, as they experience multiple oppression on the basis of ability, race, gender, age, religion, language and class. Participants spoke to the tensions between black and coloured members, and the recognition that there were no white members. This situation may be congruent with DICAG's constitution as they focused on poor disadvantaged areas, where the majority of black people reside, as a consequence of apartheid. Therefore, first and foremost, DICAG organised itself around issues of emancipation of the poor and disadvantaged communities of South Africa. A concern was raised about being aligned to a specific political party, which may alienate other potential members. A strategy linked to economic empowerment and job creation needs to

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be revisited for its relevance in the new democratic South Africa to be truly inclusive. The membership may be corrected in the future as inequities related to economics and class, and not only race, are addressed:

> *In the membership at DICAG we do not have white or Indian, the majority they are black people. I am not sure but with my experience these other cultures, for example, white people, they don't see the importance, the need of participating in an organisation maybe they can afford and can do things on their own, they don't need any advice or any support from others, you see.*

The role of caring falls in the laps of women as most fathers leave after the birth of a disabled child. *Ubuntu* (humanity) as a concept is marked by collective solidarity of the poor on survival issues. It needs to be noted that DICAG experienced the transition or shift from an organisation that has been predominantly led by mothers to one that allows membership of fathers and this phenomenon needs to be managed to facilitate inclusion without reinforcing patriarchy.

6. Excited and confused leadership

It was evident that while the achievements of DICAG were numerous there was also confusion about how the organisation should achieve advocacy through their different partnerships. A state of confusion was noted in some members regarding the role they should be playing in their different contexts. There was always a tension in explaining the role that day care centres versus local parent branches should play in relation to one another. Some participants felt that the terms of reference related to local parent branches were not clearly stated in discussions between DICAG leadership and NFU. Team development was recognised as a dynamic continuous process moving between phases of forming, storming, norming and performing. As new members joined, so the dynamics of the team (branch or PEC or NC or NEC) changed. Many participants felt that the membership had to understand DICAG's role and vision at local parent branch level, so that they would be able to stand up and represent

DICAG, with support from the national office.

There was a perceived absence of ownership of local parent branches amongst the leadership. Some participants saw partnerships and alliances with different stakeholders in non-governmental, private and public sectors, including academia, as means of further strengthening DICAG, while others were hesitant:

> *I think once again some provinces have shown that they made proper use of training manuals and information that has come from within DICAG. They are the ones that are reaping the benefits of it; others have put it on the cupboards and collected dust. But I think at the end of the day the manuals were there to encourage parents to form these partnerships, for these networks because it's not just them having those experiences. It's about making sure that children are our beneficiaries.*

Communication was identified as a major stumbling block to fostering ownership of local parent branch initiative due to the vastness of the country. Access to Internet was difficult as people have cell phones instead of landlines. Parents of children living with disabilities need to be capacitated in understanding democracy. There was also a perception that new members of the organization often did not understand or have knowledge of the history of how the organization had developed. The tendency to protect one's turf was seen as a challenge at local parent branch and provincial level. Staff rotations meant that new staff had to familiarize themselves with operations. There was a feeling that members were influenced by the marketing skills of NFU consultants without understanding the implications of proposed strategies. Tensions were evident at PEC level, as members did not voice their unhappiness with situation of "being in the dark" especially about financial matters. The drying of funds impacted negatively on the functioning of the PECs or local parent branches. NFU said to DICAG you have to establish ama-branches so that information can go straight [so] we did that we have established these branches, others are existing others, others are no longer existing.... now the funder is pulling out ..... because we have established [the branches]. We did what the funder want and all of a sudden the funder is pulling out and it really frustrates you know istaff and it really frustrates the members kwi-DICAG. Positive

comments regarding partnership between NFU and DICAG reflected the importance placed on emotional resilience and tolerance in this field of work:

> *But I think it was quite good, [as] the board …, [were able to] talk to each other, share some things, which they had never shared with each other before. … it was very emotional but it was actually a very important step for the board. For the first time they actually began to understand that they were really all in this together and really wanted the same thing. And if they really wanted to make DICAG go somewhere, they had to change some of these previous perceptions about how things were and how things weren't.*

7. Conflict in funding strategies for enhancing people-centred development Funders can strengthen DICAG's contribution to Africa.

The findings reflect that there were differences in the conceptual understanding of organisational development between DICAG members and NFU. NFU is perceived to have promoted the development of DICAG by providing funding to strengthen organisational capacity and governance. However, it seems that when NFU suggested the development of local parent branches, there was an oversight in ensuring that there was sufficient infrastructure and resources to run these branches. There was also a perception that organisational development was only implemented at the beginning of 2004, even though the partnership had existed for seven years. NFU consultants came and ran workshops in the country as part of DICAG's budget, which might have been more costly than using local consultants. NFU used sustained dialogue to raise issues related to the vision and purpose of the organisation. Tas here were also concerns raised by NFU regarding the secretariat becoming completely burnt out and stressed from fundraising to sustain the day care centres. DICAG was challenged to develop skills related to fundraising to gain independency from NFU and local branches being independent from PEC: *Thus, such active, sustained dialogue with partners has been identified a key strategy to address poverty-alleviation and the creation of an inclusive society, both with funders as well as other stakeholders, especially local and*

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provincial governments, to foster horizontal learning within an action learning approach (CDRA, 2004/5).

There was pressure on the leadership to deliver. And then there was the people that were not ready to, to progress to the level of understanding that was required. And so that created tension. In 2000 the funder came and took DiCAG back into dependency when they originally- when they found DiCAG fully developed as an organisation and they wanted to learn from DiCAG's experience.

SECTION 6

RECOMMENDATIONS

Introduction

Six key recommendations (Figure 6.1) were identified from the findings and discussions. These have been connected back to Kaplan's elements for organisational capacity (see Sections 3 and 4). While the recommendations are described individually, in reality, they are interlinked and interconnected, that is, one recommendation is considered in relation to a number of others. Thus the implementation of one recommendation will influence other recommendations made. At the end of this section key issues are highlighted that could be taken forward as DICAG continues to unfold and develop.

~~IntroductionSix key lessons and recommendations were identified from the findings and discussions. We have attempted to connect these back to Kaplan's elements for organizational capacity (see section 3 and 4). While the lessons are described individually, in reality, they are interlinked and interconnected, that is, one lesson is learnt in relation to a number of others and the implementation of a recommendation will influence other recommendations made. The reader is asked to bear this in mind, as each lesson and recommendation is considered.~~

Figure 6.1: Summary of Recommendations

1. A broad-based communication strategy and infrastructure are essential and non-negotiable
DICAG's leadership and membership need to develop effective strategies for communication so as to avoid perceptions of being dominated, undermined or marginalised. It is also essential that values and beliefs be clearly communicated across the diversity of languages, cultures and impairments.

2. A conceptual framework for the organisation needs to be developed
While no one would argue that the core to sustainability is effective organisational development and capacity, there are a number of levels to such capacity development that need to be explored, analysed and agreed to. The global experience of funders could strengthen DICAG's contribution at all levels of governance. A vital component that needs to be considered, clarified and strengthened is the area of youth development. A new lease of life is needed at leadership level and strategic planning of this process would take the organisation forward.

3. Managing boundaries
There is no doubt that continuous dialogue on issues of diversity and difference will help to address feelings of vulnerability, as members and leadership gain skills in managing boundaries between the emotional, social, physical and political dimensions evoked by disability.

4. Optimal use of human resources
The complexities of poverty mean that parents and children as human beings are the richest resource at DICAG's disposal. This resource needs to be nurtured individually for the collective good of DICAG, the nation and the African continent. Roles and responsibilities need to be clarified as new branches are developed and new members join.

5. Partnerships and alliances as a key for sustainability and continuity
Partnerships across the different sectors need to be harnessed. Co-operation between DPOs and alliances with organisations addressing common issues need to be fostered.

6. Documenting and disseminating experiences for the development of DICAG
Dialogues related to learning experiences need to be documented and published widely. Partnerships with research organisations and higher education institutions could need to be harnessed.

1. A broad-based communication strategy and infrastructure are essential and non-negotiable

Linked to the organisational structures and processes (Kaplan, 1999) it became clear from the findings that effective communication was vital for the success and sustainability of the DICAG. A first step towards resolving the perceptions of a strong administration, the 'gossip culture', and confusion related to roles and

responsibilities of committee members and staff would be to consider Peck's (1987) five communication barriers identified in community building process: expectations; prejudices and biases; differences in ideologies, theories and solutions; the need to fix, heal and solve; the need to control.

Advocacy and development cannot be separated since the one informs the other. Advocacy campaigns are informed by the activities and functions of the local parent branches and the day care centres. At the same time, national and provincial structures need to keep local parent branches informed of advocacy campaigns at these levels, so that there is cross fertilisation and consolidation of efforts. The branches that have developed new strategies for advocacy at a local level should ~~shared~~share these across the nine provinces.

The geographical vastness of South Africa and the rich diversity of languages and cultures provide evidence that organisational development is a complex matter. Technical support in the form of Internet, e-mail and telephone communication systems need to be invested in if maximum benefit of resource expenditure is to occur.

Communication with other stakeholders, such as the academic sector, needs to be encouraged, so as to utilise the potential of research for strengthening the communication strategies of the organisation. Report writing from one year to the next is inconsistent so that there is a loss of valuable experience and monitoring of information. Record keeping is not used maximally. Universities could play a role in developing management and information systems through student placements during which time they would implement specific projects. Universities would also be able to document and disseminate best practice examples.

2. A conceptual framework for the organisation needs ~~needs (?)~~ to be developed

The first element of organisational capacity is a clear and sound conceptual framework. There was evidence that one of the first steps towards organisational development needs to be the facilitation of understanding the concepts that inform DICAG's vision and practice, so as to gain ownership by the membership. Many participants felt that this process was rushed and too much focused at the national level, which contradicts NFU's vision for local parent branch development. What emerged from the findings was that there were multiple understandings of organisational development.

Firstly, organisational development focused on managerial and leadership support. This aspect included the provision of technical support in the areas of budgeting, planning, reporting etc. Another aspect was team development, which would cover many aspects usually referred to as life skills. The real challenge for organisations such as DICAG is how to harness the existing skills of its members, skills that have been learnt over a lifetime of living with a disabled child and the struggle to survive in impoverished communities. There needs to be space to unlearn the many faces of oppression (low self-esteem, violence, marginalisation, internalised oppression). Many participants echoed the fact that ~~you~~ DICAG have many capacitated parents, but that they need to be brought back into the organisation to strengthen it. As one ~~participante~~participant shared:

> The complexity of the South African society cannot be over exaggerated – geographical, diversity issues … it's very difficult for an outsider to fully understand the driving forces within the South African society … the big challenge of implementing that constitution is another thing … rights and the interests of their children must go beyond funding.

In poverty-stricken contexts, where unemployment and opportunities are limited, volunteerism needs to be proposed with caution. To be a viable strategy, it needs to be linked to skills development for viable job creation. In addition, members

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and staff need to learn how to access the different funding mechanisms in the country. As mentioned earlier, the leadership needs to budget sufficient resources and infrastructure for the development of local branches. Volunteerism should be explored within the framework of learnerships as a viable alternative towards sustained improvement in the families of disabled children.

The establishment of a Board of Trustees or a Board of Management that would function in a management and advisory capacity could help to address these concerns that otherwise undermine the effectiveness of the organisation. The board members would be committed to the vision and values of DICAG, but would be members who do not have a personal invested interest in the organisation. They could bring specific expertise to the development of policies, effective governance and strategic thinking, leadership and visioning for the organisation. This would require a change to DICAG's constitution so that it reflects the requirement that board members represent the collective interests of DICAG. The board members would have the relevant competencies to carry out their duties as board members. The board would also be responsible for developing a succession plan that provides for continuity and facilitates the replacement of board members, who would serve for a term of no longer than 3 years. New membership would be staggered to ensure that there is a core of a third of board members with ongoing experience at any one time.

The Memorandum of Understanding between DICAG and NFU appeared to have little information about local branches. The perception is that this strategy was introduced later, but with no resources available for its implementation. The strategy was negotiated through dialogues but not recorded or funded – local branches were introduced as an idea from outside of the organisation. Objectives of co-operation were not clear and there were no secondary objectives or expected outcomes. There needs to be an investigation into the allegations that the administration is too strong and undermines the work of the local branches by not representing the members effectively. There is a need for negotiated

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outcomes with funders that are flexible so as to maximise opportunities for utilising capacity and development initiatives.

Another consideration is the development of disabled youth to empower them to represent themselves at the different levels of governance within the organisation. In this way, parents will learn to 'hand over' decision-making and control to the youth, who will then be developed into the second generation of leadership for the Disability Rights Movement nationally, continentally and globally.

3. Managing boundaries

Kaplan's organisational attitude (1999) is evident in the values and beliefs reflected through the interactions within the organisation. The attitude reflects the organisational culture. During the course of this evaluation a range of emotions were experienced between the team and the funders, with interviewees and between team members as well. What was significant were the tensions created by personal health matters and work responsibilities between the team members themselves, due to juggling different responsibilities and roles. It appeared to echo what many interviewees identified as challenges in organizational development.

The experience of living with a disabled child in the family may leave one alone to deal with many fears and anxieties. Recent writings have found that trust is an essential aspect in the relationship between citizens and service providers (Gilson and Schneider, 2005; Thomas, 2004; Read, 2000). Working in the disability field has been recognised as an emotionally-laden experience (Lorenzo, 2005) since defence mechanisms are employed against the vulnerability one is exposed to. Anger and conflict management need to be addressed in order to facilitate the development of healthy productive relationshipspartnerships. Linked to this is the question of whether parents should be staff members and whether professionals should be resource persons in a way that builds capacity and organisational sustainability.

Comment [Bettina T5]: Who is the team? The employees in the DICAG office? You?

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One of the communication barriers identified by Peck (1987) was prejudices and biases. It was interesting that the international consultants were hesitant to discuss issues of perceived racial tensions in the organisation, yet the South African participants spoke openly about these differences. They recognised the need to address the fact that there was no white membership, as well as the tensions between parents and both DICAG and NFU professionals, the latter being mainly white people. As noted by Philpott and McLaren (1999) earlier in Section 2, unless the organisation creates spaces to explore issues of power, organisational capacity will be compromised. International consultants and funders need to recognise that they bring their own prejudices and biases and that they need to be vulnerable in exploring these with their counterparts. Otherwise, some form of dominance and oppression will occur. The complexity of diversity and difference needs to be understood at all levels of the organisation. Another dimension of diversity and difference that needs to be considered is the impact of the HIV/Aids pandemic on DICAG itself and ways to address this. The strategy of 'sustained dialogue' is recognised as a way forward.

4. Optimal use of human resources
Individual skills and abilities are essential for organisational sustainability. The experiences that emerged in this evaluation reflect the fact that human needs, as identified by Max-Neef (1991), become a resource in themselves. There was a repetition of the fact that capacity for sustainability related more to human resources, not only looking for funding and money. Funders need to visit local parent branches in deep rural areas to see the magnitude of the work that DICAG is doing. The human need of understanding was linked to the situation of the relatively newfound democracy, which DICAG's members needed to explore in terms of what it meant for them and their children. They need to be given the time to understand how to engage with government through advocacy campaigns that address needs such as schooling, transport, health care and family life in a way that creates a good quality of life for all. Concepts such as social change and social action to address social injustices need to be given the space for sustained dialogue. Partnerships with government departments and the

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private sector to obtain contracts for work are suggested as a way to develop financial sustainability.

The matrix of training activities revealed that there was little consistency of training from one year to the next. There did not seem to be an overall plan for human resource development. It is strongly suggested that a training audit be done to explore how skills learnt can be transferred and implemented at the different levels of the organisation, particularly at local branch level. Experience has shown that too much training results in saturation with minimal impact because of poor implementation of skills. A follow-up mechanism needs to be employed using an action learning cycle approach, which would include mentoring and on-the-job coaching. CDRA's (2004/5) experience of horizontal learning would foster peer learning through local branches visiting each other within and between provinces and so strengthen capacity. Participatory action research would combine action learning simultaneously with monitoring and evaluation.

5. Partnerships and alliances as a key for sustainability and continuity
An organisation's vision and mission brings influence to bear on the strategies that it employs. Kaplan's (1996) different phases of organisational development (dependency-independence-interdependence) is pivotal. To be effective in advocacy, DICAG needs to align itself with government policies, which have to be recognised when planning advocacy campaigns. In this way, meaningful consultation mechanisms can be established, so that the possibility of securing government support and funding will be harnessed. Examples of policies where DICAG has acted in synergy with other relevant alliance partners are the inclusive education policies, social security policies and the Children's Bill.

The innovative approaches that involve members working with local service providers, especially in education, should be nurtured and explored further. Continuity with service providers and consultants is core to organisational sustainability. Greater clarity and focus on the objectives and eventual advocacy

strategy needs to be done upfront and revisited at intervals. DICAG has managed to reach people who are not reached by government, and thus government needs to be encouraged to formalise such a partnership.

Co-operation between a DPO and a DPO needs to be fostered both nationally and internationally, so that advocacy is strengthened through partnerships and alliances around common issues. There was a realisation that support and mentoring of local parent branches is needed for growth in the initiatives of the new democracy until there is sufficient infrastructure to sustain the initiatives.

Thus, such active, sustained dialogue with partners has been identified as a key strategy to address poverty alleviation and the creation of an inclusive society, both with funders as well as other stakeholders, especially local and provincial government, to foster horizontal learning within an action learning approach (CDRA, 2004/5).

6. Documenting and disseminating experiences ifor the development of DICAG

n civil society formations (public) and academic forums and formatsMaterial resources are essential for building organizational capacity. Children's issues are critical at this stage in South Africa and Africa. While it is great to have *"conversation partners",* it is crucial that the fruits of these dialogues are documented as the dialogues are potentially the seedbed for rich learning experiences. The history of the organisational and the cyclical nature of development would then be appreciated by new members. Frustrations would be channeled into productive activity. Tools such as storytelling are needed to capture the real life capture experiences of parents and disabled children in reports. There is a need to further explore thevarious partnerships for with academic institutions to assistance in documenting partnerships and lessons learnt, so as to contribute actively to policy initiatives (development and

implementation). These documents also become essential material for monitoring and evaluation activities.

Both evaluation reports (Philpott and McLaren, 1999; Hertzberg and Comninos, 2001) highlight the time constraints for the evaluation as a limitation. DICAG should develop a participatory monitoring and evaluation system that is ongoing and covers all nine provinces. This evaluation team echoes the same concerns, with the need for an action learning approach related to ongoing monitoring activities that would contribute to a participatory evaluation process. It is possible that the nine provinces could be covered over a three-year cycle, with three provinces being evaluated each year using a participatory action research approach. Research as a means for monitoring and evaluation needs to be demystified so that continuous action-reflection occurs. The feedback on this evaluation could be used as a crisis intervention tool.

Thus, NFU would need to consider continue its funding so as to consolidate lessons learnt and to see the development of the local branches that it was instrumental in introducing through to completion, i.e. documented experiences of different experiences, in partnership with higher education institutions and research organisations..

> *Just exactly that, that whilst we have some many progressive qualities within the country, DICAG has a role to play in Africa. With Our experiences in the last 10-11 years of democracy we have a definite role, but also capacity to share with other parent organizations on the continent. Also that when it come to children with disabilities, yes we do have inclusive education polices. But not all children are able to access that. And so there will always be a place with in special educate or day care centre for a child and it is our role as an advocacy organization to make sure that child receives that support.*

Information dissemination was seen as one of DICAG's primary activities. Some participants saw access to information as a tool for empowerment of both disabled children and their parents. There was potential for local parent branches to act as a vehicle to facilitate access to information:

I think the most important or fundamental aspect that DICAG would focus on is giving parents that access to information. … The first thing would be to set that person up with the closest local parent branch in the area. But also to forward relevant information about the child's disability … There is no information for those branches and support groups that we have established and the purpose of establishing ama-support groups or ama-branches was to make sure that you know parents came together and share the experience and as they are waiting well …

CLOSING REFLECTIONS

When forging a partnership, partners need to continuously reflect on the context, discuss differences and learn from each other while respecting diversity. Communication and dialogue are critical components to building meaningful relationships. DiCAG, being a revolutionary activist organisation, was reactionary and not into investing time for developing clear terms of reference for meaningful partnerships. The resulting perception is that they tended to focus on the agenda at hand, which was a need for funding. On the other hand, there is also a perception that NFU, by virtue of having the power as a much needed funder, could easily find itself drawn towards manipulating decisions related to the development of the organisation. This highlights that it would be time well invested to strengthen the strategic value of sustained dialogue so as to clarify conceptual understanding between partners at ALL levels of the organisation.

DICAG needs to develop a structure for continuous internal monitoring and evaluation of their activities since the external evaluations conducted by NFU were found to be superficial and tended to underplay DICAG's achievements and growth. This evaluation only looked at two provinces, so that findings cannot be generalised or transferred across the provinces. The evaluations done in 1999 and 2001 also mentioned the limitations of not covering all provinces. A suggestion is that evaluations are seen as in three year cycle. As such, three provinces would be evaluated per year, so that at the end of the three years, all nine provinces would have participated in the evaluation cycle.

Leadership development is critical for implementing the organisational vision and strategy. This development should be in line with changes within DiCAG, and NFU would need to continuously reflect on their scope of practice and how this links to action plans. Therefore, without succession planning DICAG'S existence, stability and sustainability are threatened.

DICAG needs to develop an organisational culture that embraces and manages diversity and difference proactively in order to redress inequities of the past. Within this context, issues of developing a diverse membership would provide an opportunity to address this difference.

Funders and government need to consider issues of financial support in an organisation run by volunteers living in impoverished contexts. In the absence of financial sustainability, tensions and lack of motivation between members occurs (Philpott and McLaren, 1999). Limited funding and capacity has made visibility of DICAG difficult. Material help was needed together with capacity building. Parents had few material resources to support their own families, let alone their training and involvement in other organizational matters and running of day care centres.

DICAG's aspiration and endeavours links and responds to the eight United Nation's Millennium Development Goals (UN, 2000). The United Nations suggests that member states should strive to achieve the goals by 2015. However, for DICAG to realize their aspirations related to the Millennium Development Goals, support from both internal and external agencies is of paramount importance, especially government and international agencies such as NFU.

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APPENDICES

APPENDIX 1
TERMS OF REFERENCE

NFU

Norsk Forbund for Utviklingshemmede

Norwegian Association for Persons with Developmental Disabilities

Postboks 8954
Youngstorget
0028 Oslo, Norway
Tel: +47 22 39 60 50 Fax: +47 22 39 60 60
E-mail: Bettina.thorvik@nfunorge.org

Terms of Reference

For an external evaluation of the development co-operation between Disabled Children Action Group (South-Africa) and Norsk Forbund for Utviklingshemmede (NFU).

September 2005

Background

DICAG is a cross-disability national organisation of parents of children with disabilities in South Africa. It began life in 1993 as a programme of Disabled People South Africa (DPSA) in response to a growing recognition of the role played by parents in their children's development. In September 1997 DICAG registered as an independent membership-based organisation.

DICAG's development goal is that "[a]n increased number of children with disabilities will be empowered and live and fully participate within conducive, inclusive and integrated environments that enable them to feel equal, protected, accepted and adequately cared for."

DICAG is an advocacy and children's right organisation. They consider their key role to monitor the implementation of plans on all levels of government, to contribute effectively to the policy process of government in the interest of disabled children and to participate in activities that seek to improve the quality of life of children with disabilities and their families. DICAG engage in activities at the national, provincial and local level in South-Africa.

By the end of 2004 DICAG had 3151 officially paid up individual members, some of them are individual parents of children with disabilities, some are children, and an app. 5 % and 10 % are associates and interested individuals. 1200 of the parents have formalised themselves into 86 local parent branches.

NFU has had a partnership agreement with DICAG since March 1997. Funding was originally earmarked for DICAG's Provincial Advocacy Leadership and Policy

Development Programme (PALP). From 1999 the funding was directed toward DICAG in general. An external evaluation in 2001 emphasized the need of DICAG to strengthen and polish their role as an advocacy organisation. This has since been the major task of NFUs support to DICAG, with emphasis at supporting the general organizational development, its role as an advocacy organisation and the advocacy skills of parents, particularly at the local level. Despite being an advocacy organisation, local branches also run day care centers.

NFU is a national advocacy organisation that fights for the inclusion of persons with developmental disabilities in society. NFU insists on the ultimate responsibility of government to provide the services required to ensure that every individual has equal opportunity for participation. NFU's development co-operation reflects these aims. NFU provides support to democratic, membership-based parents' organisations or networks that advocate for the full participation and inclusion of people with developmental disabilities and children with disabilities. NFU supports capacity building and organisational development, but does not support service provision or service-oriented programmes.

The co-operation agreement between NFU and DICAG ended on 31 December 2004. An evaluation of the partnership has been planned as an important integrated part of the co-operation, so that both NFU and DICAG have the possibility to adjust the course of their work according to the suggestions made by the evaluation.

The **aims** of the evaluation:
4. To explore the achievements of the DICAG-NFU's partnership since 1997.

5. To determine strategies for sustainability in order to assess DICAG's institutional viability nationally and internationally.

The principal objectives of the evaluation:

1. **To review DICAG's development as an organisation and assess the scope and impact of its lobbying and advocacy work since 1997**

    Review *briefly* the political, legal and institutional climate for children with disabilities in South-Africa.

    Assess DICAG's organisational and membership structure; particularly with emphasis on the communication and sharing of information between all levels and staff, e.g. the implementation of DICAG's constitution and draw out any implications for effectiveness in achieving stated objectives.

    (i)   How has the situation for parents changed by being members of DICAG and having had training in organisational development?

    (ii)   Assess DICAG's relationship with other stakeholders, especially in relation to government (particularly education, health and social development), and higher education institutions

    Identify underlying factors/determinants to success/failure, particularly related to the two different tasks of the organisation:

      (i)   lobbying

      (ii)   Assess how the support of day care centres has influenced DICAG's role as an advocacy organisation

2. **To assess NFU's approach and contribution to the development of organisational structure and content on all levels of DICAG (national, provincial and local).**

What has been NFU's methodology when seeking to transfer its added value to DICAG? Provide recommendations.

Review *briefly* DICAG's development since the establishment of the NFU partnership in 1997 focusing on stated goals, policy development and principal activities undertaken.

Assess the impact of NFU's added value, and identify areas where NFU support has been particularly effective/ineffective.

3. **Assess DICAG's long-term capacity and plans of sustainability as an advocacy organisation and make appropriate recommendations for future institutional sustainability.**

Assess what impact the evaluation of HESO from 2001 had on the co-operation between NFU and DICAG, and the organisational development of DICAG.

Make recommendations regarding DICAG's and NFU's future cooperation with parents' organisations in Sub-Saharan Africa.

Use of the evaluation

DICAG will use the evaluation to further work on issues where the organisation needs strengthening. This might regard both polishing the structures of a democratic member-based organisation as well as their advocacy skills. It will also use the evaluation to work further on the sustainability of the organisation.

NFU will use the evaluation to strengthen its existing and future international work, particularly their co-operation with parents' organisations and networks. Thus the aim of the evaluation should be to assess the relevance of objectives, efficiency, effectiveness, impact and/or sustainability of NFUs international work.

Methodology

The evaluation team will use a naturalistic qualitative research approach, because it will allow for a flexible yet in-depth inquiry. This approach allows for engagement and active involvement of DiCAG membership in the research process, so that they will not become the objects of evaluation, but to all intents and purposes, will find mutual learning and benefit from participation in the process.

The evaluation will be carried out in the natural contexts of the parents, the places where they live and interact. A qualitative research approach emphasizes broad understanding and deep insight rather than presenting numbers.

The methodology will encompass participatory action research (PAR). PAR methodology allows for a flexible approach, responsive to emergent issues as the study progresses, so that the study remains relevant. Bailey (1997) comments that qualitative data are rich and powerful with the potential for revealing complexity, which resonated with the purpose of this study. The factors that impact on the development of people are complex.

Where easy accessible quantitative data is available this will be used to broaden the picture.

Data generation

1. Document analysis: Evaluation reports; provincial reports and annual reports for the period of DiCAG and NFU partnership will be some of the documents to be reviewed.

2. Focus group discussions: Provincial parent organisations; National Executive board, and provincial development committees of DiCAG staff members (provincial co-ordinators and administrative staff) and local parent branches.

3. Key informant interviews: Bernadette Leideman as director; Washeila Sait as previous director; Bulelwa ka Toni as the organisational development consultant; NFU regional consultant in Zimbabwe.

4. In-depth interviews: Christina Sadiki, Mbuzi Nzimande, A.K. Dube – fundraising consultant, Samaita associates; government officials [social development (D. Pooe); education (Laetitia Bremner) health]; Sue Philpott – consultant researcher; Prof Ruth Watson; Kashifa Lagerdien, Fasloen Adams (UCT researchers with DiCAG in Oceanview, Western Cape), and persons from NFU – Norway Anne Ragnhild Breiby and Andrew Preston. (The contractors stand free to extract two from this list to not be interviewed, except from the two former and the two latter. This is due to the addition of the two latter persons from NFU after the agreement of the budget).

The following measurement tools will be used in the focus group discussions and interviews:

- Wheel of opportunities (Lorenzo and Sait, 2000), based on the UN 22 Standard Rules for the Equalisation of Opportunities.
- Spiderweb of community participation (Rifkin and Kangere, 2001) explores five factors, namely, needs assessment, leadership, management, resource mobilisation, and organisation.

- Kaplan's organisational development triangle (Kaplan, 1998) identifies the features of organisational life: conceptual framework, organisational attitude (culture); vision and strategy; structures and procedures; individual skills, abilities and competencies; and material resources. We will combine this with Kaplan's phases of organisational development, namely, dependence, independence and interdependence.

Reflective journals: researchers will keep these during the preparation and evaluation

Evaluation team
Director and senior lecturer Ms. Gubela Mji at the Centre for Rehabilitation of Stellenbosch University

Senior lecturer Ms Siphokazi Gcaza at the Centre for Rehabilitation of Stellenbosch University

Senior lecturer Dr.Theresa Lorenzo at the Division of Occupational Therapy in the School of Health and Rehabilitation Sciences at the University of Cape Town.

The evaluation team is free to draw on any kind of other human resources they find necessary to conduct the evaluation. There are however, no possibilities for extending the budget over 180 000 rand.

Resource persons from DICAG and NFU

On DICAG's behalf Bernadette Liedemann is responsible for providing the necessary information and contact with informants and providing the above team with the necessary documented information.

DICAG co-ordinators in the province will be requested to assist with finding suitable venues and organising matters, in liaison with the researchers and research associate. On NFU's behalf, Bettina Thorvik is responsible for providing the necessary information and contact with informants and providing the above team with the necessary documented information.

Any delay caused by not being provided with necessary information by any of the two organisations, shall be reported.

Reporting and Timing
The evaluation will be conducted during the last quarter (September-November) of 2005. Prior to visiting the field, the evaluator(s) will read through available documentation and become familiar with the goals and strategies of DICAG, the development cooperation strategy of NFU and the agreements that exist between the parties.

If the evaluation team during their research discover issues not covered by the objective of the evaluation and which they find important/necessary to include in the report, these must be discussed with NFU and DICAG.

Preparation of evaluation materials: September
Data generation: October

Data analysis and member checking: October/November
Report-writing: drafting report in November/December
Feedback workshop: Present a draft of final report – 30th November
Send report in 15th December.
Final submission: 31st January 2006

APPENDIX 2
INTERVIEW SCHEDULE

Guideline: 1 hour

1. How do DICAG members and staff understand disability, poverty and human rights?
   - How does this understanding impact on the activities and organizational development?
   - How these concepts link to advocacy and development?
   - Contextual issues – socio-economic, political (policies), cultural.

2. What are the roles and responsibilities of members and staff at the different levels of the organization?
   - How is communication and information disseminated from National – provincial – local and vice-versa?
   - How is capacity building devolved to the local branches?
   - How effective has this been?

3. How do the activities of DiCAG contribute to its organizational development as an advocacy organisation?
   - What is the role of these activities in organizational development?
   - How have the different strategies or tools have been effective e.g. day care centers, capacity building workshops, advocacy manuals?

4. How does the relationship between DICAG and DPSA impact on organisational development?
   - Explore the nature of the relationship with DPSA. How did this change?
   - Check the perception of DICAG's failure to restrategise after separating from DPSA
   - How has DICAG accessed the different racial groups; peri-urban and rural areas; poor.

5. How has the relationship with NFU promoted or hindered organizational development?
   - How did NFU fulfill their promises?
   - How have cultural factors influenced the organization? Language, stereotypes and biases, images used
   - What was the rationale for staggered funding?
   - How did this impact on DICAG's organizational development?
   - How did trainers or consultants hinder or promote organizational development?
   - What changes occurred?
   - What solutions/strategies that were generated?

6. How do the expectations of the different funders affect the organizational development of DICAG?

- How has DICAG managed these different expectations?
- How do the different expectations compliment each other and influence outcomes?

7. What lessons have been learnt from the partnerships?
- DICAG as an indigenous unit?
- Potential to generate and contribute to indigenous knowledge systems related to solutions and strategies
- Lessons about sustainability

APPENDIX 3
DOCUMENTS REVIEWED

- Co-operation between DICAG and NFU for the period March 1997 to December 2001

- Project visits for: 15–27 November 1999, 13–21 November 2000 and 4–7 May 2001

- DICAG Annual Report (1999)

- Philpott, S. and McLaren, P. (1999). Evaluation of the Disabled Children's Action Group – (DART) April 1999

- DICAG (2000) Building towards an equal millennium for all. Progress report January–June 2000

- DICAG Report on Activities (January–May 2001)

- Hertzberg, A. and Comninos, S. (2001) From action programme to membership organization – Evaluation of the Disabled Children's Action Group (DiCAG) organization as background for training and advocacy March– April. Preliminary findings of March 2001 DICAG evaluation

- DICAG Annual Report (2002)

- DICAG and NFU agreements revised agreements 2002–2004

- DICAG Progress Report (January–June 2003)

- DICAG Annual Review (2003)

- DICAG Status Report November 2004

APPENDIX 4

RECOMMENDATIONS FROM NFU VISIT REPORTS 2000–2004

Date of visit	Recommendations/agreements/conclusions of visits
Expected results of the co-operation between DICAG and NFU (NFU-DICAG co-operation 2000, summary of aims and objectives)	Parents of children with disabilities trained in leadership and organisational skills. Parents of children with disabilities trained in advocacy work and informed about national policies and legislation. Meetings held with national and local authorities at which rights of children with disabilities are promoted. Proposals for change in legislation are submitted to government. Regional co-operation and networking with other organisations of parents of children with disabilities. DICAG's capacity as an organisation, both at national and provincial level consolidated and developed. Information work directed at the government at all levels and the general public.
13–21 November 2000 (Project visit to DICAG, South Africa, Oslo, May 2001	1. Do an organisational review of DICAG as the first step in a participatory organisation development process. The review should consider membership, political structure and staffing in relation to DICAG's objectives. 2. Do a national strategic plan that is to be approved by the national congress/national executive. The plan should set targets for advocacy, parent empowerment and organisational development (structure, roles and responsibilities). 3. The national plan should include training strategies within three targeted areas: ● Advocacy – taking into account the changed political conditions of people with disabilities at national, provincial and local levels since 1993; ● Empowerment of parents, youth and children; and ● Organisational development of the membership organisation. 4. A plan of action should be made for each province, based on the national plan developed. 5. An appropriate model for project cycle management should be used as a basis for all plans developed so that adequate monitoring and evaluation is facilitated at every level within the organisation. 6. The training needs of the organisation should include: ● High level capacity building of office bearers and staff (planning, management, financial etc.). ● General capacity building of members (organising themselves, lobbying, early childhood development, their rights etc.).
20–21 February 2002 (Project visit to DICAG, Oslo May 2002)	Follow up DICAG's policy development work, grassroots re-mobilisation and branch development. Provide feedback on draft documents when available. Facilitate a follow-up workshop in the second half of 2002.
6–8 December 2002	Follow up DICAG's work aimed at improving internal communication and co-operation within the National Council and between council members and administration. Provide feedback on documents outlining communication, structure, roles etc. Workshop on how to build an advocacy organisation, including policy development tools. Determine whether NFU can do more to assist DICAG at the local level as requested by DICAG in workshop.

27 June–5 July 2003 (Visiting report DICAG, September 2003)	DICAG has a long way to go in developing the understanding of the role and work of the local branches in the rural areas. The administration has a huge task ahead of them in ensuring that their knowledge is being shared with members. NFU's regional consultant, Lilian Mariga, will to some extent follow up and train the local branches where that is wanted and possible. Still, NFU's main focus will be at the national level: national council and national board. It will in turn be their role to train the local branches. During NFU's next visit in April/ May 2004, NFU will attend DICAG's national congress where the organisation's manifesto will be a main issue. The manifesto has been discussed at grassroots level and the feedback taken into account in the manifesto which will be proposed at the national congress.
24 April–1 May 2004 (Visiting report DICAG May 2004)	National Council and National Executive seem to be insecure about their roles. Too much power and decisions are with the national administration. Organisational structure: the provincial level needs to be recognised and strengthened. The administration should make sure that they are not undermining the provincial level. Staff: DICAG complains of a lack of staff. DICAG has a national co-ordinator, secretary, accountant, driver and two regional co-ordinators working full time. None of the organisations that NFU co-operates with have this number of employees. DICAG believes that the development of membership and local branches are delayed by a lack of staff. On the contrary it is possible to claim that the current development indicates that the members and particularly the elected people at local and provincial level are not given the necessary responsibility to develop the organisation. … Members' willingness to work voluntarily could disappear proportionately with the employment of staff. The administration must start believing in the National Council and let them take the responsibility for which they were elected. NFU believes the administration underestimates the National Council members when stating that the council members are not capable of giving workshops and seminars. … if the organisation does not manage to capacitate and build upon parents' knowledge and voluntary work, DICAG will face a very difficult financial future. According to the National Co-ordinator, DICAG will give priority to provincial co-ordinators on the expense of the national office. If DICAG is to survive and prosper as a national organisation, the importance of having a co-ordinating office at the national level should not be underestimated.
5–7 November 2004 (Visiting report DICAG November 2004)	DICAG's newly elected chairperson impresses NFU in his clear thinking both when it comes to organisation development and understanding his role as the elected leader of DICAG as being an advocacy organisation. …In DICAG there seems to be several unfortunate dependencies which have strengthened the administration on behalf of the elected board. Over the years, DICAG has had what the previous evaluation referred to as a "gossip culture". This was discussed during NFU's previous visit and hopefully this can help the members to focus on organisational issues instead of spending time and energy making problems. During the workshop, NFU informed about the regional network in Southern Africa. Inclusion Africa and Inclusion International. This was new information to most of the participants at the workshop. DICAG's attendance is often taken care of by DICAG's administration. And it seems like little information is trickling down to the board and the regular members – with a few exceptions … An example of this is the last regional network meeting in Tanzania. DICAG is a member of this network and a few weeks after the NFU's visit to South Africa a regional network meeting was taking place in Dar es Salaam. The chairperson's attendance was refused by the national co-ordinator, who attended the network meeting alone. DICAG's board and members who attended the workshop were afraid that the end of the relationship with NFU would mean an end to the development of local branches. Yet, the development of local branches has received little or no funding. What will be lacking is NFU's knowledge sharing and push towards getting the parents more involved in the organisation. It is NFU's hope and concern that the administration and the organisation's string branches will feel a responsibility to develop the local branches and thereby the organisation further. …