

**A participatory approach to the design of a
child-health community-based information system
for the care of vulnerable children**

Elaine Byrne

A thesis submitted in fulfilment of the requirements for the degree of Doctor
Philosophiae in the School of Public Health, University of the Western Cape

September 2004

Supervisors: Dr Uta Lehmann, University of the Western Cape and Professor
Sundeeep Sahay, University of Oslo

Keywords

Information Systems Design,
Community-Based Information Systems,
Health Information Systems,
Vulnerability,
Child Health,
Participation,
Communication,
Critical Social Theory,
Structuration Theory,
Action research

Abstract

A participatory approach to the design of a child-health community-based information system for the care of vulnerable children

E. Byrne

Ph.D. Thesis, School of Public Health, University of the Western Cape

The existing District Health Information System in South Africa can be described as a facility based Information System, focusing on the clinics and hospitals and not on the community. Consequently, only those who access health services through these facilities are included in the system. Many children do not have access to basic health and social services and consequently, are denied their right to good health. Additionally, they are excluded from the routine Health Information System. Policy and resource decisions made by the District Managers, based on the current health facility information, reinforces the exclusion of these already marginalised children.

The premise behind this research is that vulnerability of children can be tackled using two interconnected strategies. The first is through the creation of awareness of the situation of children and the second through mobilising the commitment and action of government and society to address this situation. These strategies can be supported by designing an Information System for action; an Information System that can be used to advocate and influence decisions and policies for the rights of these children; an Information System that includes all children.

An interpretive participatory action research approach, using a case study in a rural municipality in South Africa, was adopted for the study of a child-health Community-Based Information System. The context in which the community is placed, as well as the structures which are embedded in it, was examined using Structuration Theory. This theory also influenced the design of the Information System. As the aim of the research is to change the Information System to include vulnerable children, a Critical Social Theoretical and longitudinal perspective was adopted. In particular, concepts from Habermas, such as the creation of a public sphere and the 'Ideal Speech Situation', informed the methodology chosen and were used to analyse the research undertaken.

Based on the research conducted in this municipality, four main changes to the Health Information System were made. These were:

- determination of the community's own indicators;
- changes in data collection forms;
- creation of forums for analysis and reflection, and;
- changes in the information flows for improved feedback.

Other practical contributions of the research are the development of local capacities in data collection and analysis, the development of practical guidelines on the design of a child-health Community-Based Information System, and the development of strategies for enabling participation and communication.

In line with the action research approach adopted, and the desire to link theory and practice, the research also contributed on a theoretical level. These contributions include extending the use of Structuration Theory, in conjunction with Habermas' Critical Social Theory, to the empirical context of South Africa; addressing the gap of Community-Based Information Systems in Information System design; extending the debate on participation and communication in Information Systems to 'developing' countries, and developing generalisations from a qualitative case study.

September 2004

Declaration

I declare that *A participatory approach to the design of a child-health community-based information system for the care of vulnerable children* is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Elaine Byrne
September 2004

Signed:

Acknowledgements

Most of the fieldwork presented in this thesis was carried out by the staff of the UThukela District Child Survival Project. Their dedication and commitment to the work is appreciated. In particular I would like to thank:

- the Community Field Facilitators: Simphiwe Kunene; Philani Mabaso; Happy Mohlakoema; Bongani Mthabeli; Sizo Ndaba; Sbusiso Ngubane; Zwelakhe Nyathi, and Nimrod Xaba;
- the Community Development Officer, Noma Mtshali;
- the HIV/AIDS project leader, Zanele Mchunu, and;
- the IMCI manager, Chris Gibson.

Thanks must go also to the District Department of Health staff, in particular Si-bongile Maphalala, the area manager for OKhahlamba Municipality, for also contributing to the fieldwork. Thanks also to Monika Holst, UThukela District Child Survival Project leader, Chris Gibson IMCI manager and Tim Kerry IMCI leader, for providing the necessary financial, managerial and technical support. Above all else though, gratitude must be expressed for their commitment to the project and their continuous motivation.

For their contribution to the development of the community-based indicators, and for sharing their experience in the Health Information Systems in the UThukela District, I extend my gratitude to Maria Hlombe, Community Health Committee member, Okhombe; Diane Govender, District Information Coordinator, and Bernard Gaede, CEO, Emmaus Hospital. For the future implementation of the Community-Based Information System I must commend the enthusiasm of the District staff, in particular the District Manager, Lorraine Brysiewicz and the recently appointed District Information Officer, Alta Odendaal. I hope that the work in OKhahlamba Municipality will spread with their enthusiasm, dedication and insightfulness to the rest of the UThukela District.

To all the people, who are too many to mention by name, who gave of their time in the interviews, focus group discussions and meetings, I hope that the outcome of this research will assist in the monitoring of the situation of the children of the UThukela District.

Gratitude is also extended to the people outside the UThukela District for their

comments on the numerous papers I have written and for sharing their experiences with me, namely: the IMCI Community Component National Task Team; the Child Health Directorate at the National Department of Health, and UNICEF (Pretoria).

Academically, the support, guidance and friendship of both my supervisors, Dr. Uta Lehmann (University of the Western Cape, South Africa) and Prof. Sundeep Sahay (University of Oslo, Norway), is deeply appreciated. Their pragmatism and gentle persuasion from the beginning, and encouragement throughout the process, made the road to completion much smoother. Appreciation is also extended to the staff and students from the University of Eduardo Mondlane, Mozambique and the University of Oslo, Norway. I also wish to thank all my colleagues at the University of the Western Cape for organising meetings, seminars and all the good times we had together. I also extend my gratitude to the many reviewers who commented on papers I have written, presented and published.

Financial assistance was received from the National Research Foundation of South Africa for the first year of my study. My attendance at many conferences was possible through funding received from the British Commonwealth, the Medical Research Council of South Africa and the University of the Western Cape. The fieldwork was funded through a World Vision/USAID grant to the UThukela District Child Survival Project and a National Research Foundation of South Africa Health Information Systems Project grant to the University of the Western Cape.

Gratitude is also expressed to Jennie Fidler for doing the copy editing of the thesis, whilst still remaining a friend. Lastly, but most importantly, my gratitude goes to Bob Jolliffe and my boys, Peadar, Govan, Finn and Aidan for their love and support over the years.

And, finally, I include the usual caveat, that I am responsible for any errors and shortcomings of this dissertation.

Contents

Keywords	ii
Abstract	iii
Declaration	v
Acknowledgements	vi
Acronyms	xiv
List of Figures	xv
List of Tables	xvii
I Setting the Stage	1
1 Problem addressed and background	2
1.1 Introduction	3
1.1.1 Absence of Child-Health Community-Based Information Systems	3
1.1.2 Constitution and legislative framework for children	5
1.1.3 Child-Health Information Systems	6
1.2 The case study	8
1.2.1 Physical and demographic conditions	10
1.2.2 Socio-economic status	12
1.2.3 Health status	16
1.3 Conclusion	19
1.4 Overview of thesis	20
2 Theoretical perspective	23
2.1 Introduction	24
2.2 Use of Structuration Theory and Critical Social Theory	25
2.2.1 Context	25

<i>CONTENTS</i>	ix
2.2.2 Process of design	30
2.2.3 Output	33
2.3 Application of theory in contemporary IS research vis-a-vis UThukela District case study	34
2.3.1 Contemporary application of Structuration Theory in information system research	34
2.3.2 Contemporary application of Critical Social Theory in information system research	36
2.4 Conclusion	39
3 Vulnerability and Information System design	42
3.1 Introduction	43
3.2 Addressing vulnerability through IS design	43
3.3 Meaning of vulnerability	46
3.3.1 Vulnerability and HIV/AIDS	47
3.3.2 Social exclusion and marginality	49
3.3.3 Globalisation and exclusion	49
3.4 Meaning of vulnerability in this research	51
3.5 The development of the District Health Information System	54
3.5.1 The National Health Information System	54
3.5.2 Provincial Health Information Systems	59
3.5.3 The District Health Information System	60
3.6 Conclusion	63
II Research approach and context	65
4 Research design and methodology	66
4.1 Introduction	67
4.2 Role of the researcher	67
4.3 Research approach	69
4.3.1 Philosophical perspective: Interpretive	69
4.3.2 Research methodology: Action Research	71
4.3.3 Time frame: Longitudinal	74
4.4 Mode of analysis	80
4.5 Ethics statement	86

5	Social and political processes	88
5.1	Introduction	89
5.2	Restructuring the health services	90
5.2.1	Transformation of local government	91
5.2.2	Restructuring the health services	92
5.2.3	Changes and challenges in the restructuring process	94
5.2.4	Situation of UThukela District Health Services	97
5.2.5	UThukela District Health Information System	100
5.2.6	Community-based information	102
5.3	Social traditions	105
5.3.1	Social organisation	105
5.3.2	Political structures	106
5.3.3	Communication	107
5.3.4	Health and child-care	108
5.4	Conclusion - implications of structuration process in IS design . . .	109
5.4.1	Sensitising function	109
5.4.2	Opportunities and challenges raised	110

III Process and output 115

6	Development process of the CBIS	116
6.1	Introduction	117
6.2	Overview of the design process	117
6.2.1	Client-System Infrastructure	118
6.2.2	Diagnosing	120
6.2.3	Action planning	123
6.2.4	Action taking	124
6.2.5	Participatory evaluation	133
6.2.6	Specifying learning and revising action	135
6.3	Conclusion	136
6.3.1	What is the vision of the community for the health of their children?	136

6.3.2	How does the existing DHIS assist with the assessment of the situation of children's health and in identifying action to be taken with respect to the vision of the community?	137
6.3.3	How can information flows be designed that facilitate the integration of the CBIS with the formal health facility IS? . .	137
7	Output of the CBIS	139
7.1	Introduction	140
7.2	Determination of the community's indicators	140
7.3	Changes in data collection tools	142
7.4	Creation of forums for analysis and reflection:	143
7.5	Changes in the information flows for improved feedback	148
7.6	Conclusion	151
IV	Analysis and implications of research	152
8	Rethinking participation	153
8.1	Introduction	154
8.2	Participation in IS design	155
8.3	Participation in the case study	158
8.3.1	Participation in the process of CBIS design	158
8.3.2	Participation in the revised HIS	160
8.4	Discussion	164
8.4.1	Obligatory community involvement	164
8.4.2	Need for multi-level and multi-sectoral participatory processes	165
8.4.3	Politics of participation and 'non-participation'	166
8.4.4	Developing the capacity to participate and to take decisions	167
8.5	Challenges still to be addressed and conclusion	169
9	Constructing local meaning	171
9.1	Introduction	172
9.2	Theoretical perspective	173
9.3	Communication in the process of designing a CBIS	178
9.3.1	Creation of shared vision	178
9.3.2	Local meanings for childhood illnesses	179

9.3.3	Connecting with broader networks	182
9.3.4	Communication and social processes	183
9.4	Criteria of Ideal Speech Situation revisited	184
9.4.1	Extent of access	184
9.4.2	Degree of autonomy	185
9.4.3	Rejection of hierarchy	186
9.4.4	Rule of law	186
9.4.5	Quality of participation	186
9.5	Conclusion	188
10	Theoretical contributions	190
10.1	Introduction	191
10.2	Extending Giddens' Structuration Theory	191
10.2.1	South African Context	191
10.2.2	Empirical use of theory	192
10.2.3	Integration of Critical Social Theory	194
10.3	Design of CBIS	195
10.3.1	CBIS inadequately addressed in IS	195
10.3.2	Understanding of community	196
10.3.3	Integration of systems	197
10.4	Extending debate on participation to non-western context	199
10.5	Going beyond formal communication	201
10.6	Scalability and sustainability	202
10.6.1	Sustainability	202
10.6.2	Scalability	203
10.7	Conducting Action Research	205
10.8	Generalisation	205
10.8.1	Empirical to empirical	207
10.8.2	Empirical to theoretical	209
10.9	Conclusion	210
11	Practical contributions	212
11.1	Introduction	213
11.2	Designing a CBIS using participatory action research	214
11.2.1	Client-system infrastructure	214

<i>CONTENTS</i>	xiii
11.2.2 Diagnosing	215
11.2.3 Action planning	216
11.2.4 Action taking	217
11.2.5 Participatory evaluation and sharing of experiences	217
11.3 Extending the debate on participation	218
11.4 Going beyond formal communication	221
11.5 Addressing scalability of CBIS	222
11.5.1 Expansion within the District	224
11.5.2 Expansion beyond the UThukela District	226
11.6 Conclusion	227
V Bibliography	228
VI Appendices	245
A Observation tool	246

Acronyms

BPR	Business Process Re-engineering
CBIS	Community-Based Information System(s)
CBO	Community-Based Organisation(s)
CRC	Convention on the Rights of the Child
DHIS	District Health Information System(s)
DHS	District Health System
FGD	Focus Group Discussion(s)
GDP	Gross Domestic Product
HIS	Health Information System(s)
HISP	Health Information Systems Project
HSRC	Human Sciences Research Council
ICT	Information and Communication Technology(ies)
IMCI	Integrated Management of Childhood Illness
IS	Information System(s)
KPC	Knowledge, Practice and Coverage
NGO	Non-Governmental Organisation(s)
NHISSA	National Health Information Systems for South Africa
NPA	National Programme of Action for Children
PD	Participatory Design
PHC	Primary Health Care
PHRC	Provincial Health Restructuring Committee
PLA	Participatory Learning for Action
PRA	Participatory Rural Appraisal
RDP	Reconstruction and Development Programme
RRA	Rapid Rural Appraisal
RTHC	Road To Health Card
SAHR	South African Health Review
TDCSP	UThukela District Child Survival Project
TLC	Transitional Local Council(s)
TMC	Transitional Metropolitan Council(s)

List of Figures

1.1	Municipalities of KwaZulu-Natal	11
1.2	Outline of thesis	22
2.1	Dimensions of duality of structure	27
2.2	Social interaction in Habermas typology	32
3.1	Proposed District Information Model with all components	61
4.1	Underlying philosophical assumptions	70
4.2	Participatory action research model	72
4.3	Praise poem at end-of-project evaluation feedback	77
4.4	Poster feedback session from mid-term evaluation	78
4.5	Group feedback session at mid-term evaluation	79
4.6	Defining indicators from field data	83
4.7	Participatory analysis of data	84
4.8	Three posters depicting TDCSP activities	85
4.9	Poster reflecting the CBIS development process at donor meeting	86
5.1	Proposed information flow for the UThukela District	101
5.2	Actual data and information flow for UThukela District	103
6.1	Identification of duty bearers and role players	119
7.1	Community Health Worker weighing child during household visit	143
7.2	Causes of childhood mortality	144
7.3	Triple 'A' cycle	145
7.4	Community Health Workers compiling statistics at their monthly meeting	147

7.5	Community Health Facilitators collating monthly community-based data	148
7.6	Proposed community information flows	149
7.7	Proposed District information flows	150

List of Tables

1.1	Changes in names of the case study area	10
1.2	Population of UThukela District by Municipality	12
1.3	Sources of income	14
1.4	Income-generating activities	15
1.5	Child Health Statistics	16
2.1	Categorisation of application of Structuration Theory to IS research	35
2.2	Categorisation of application of Critical Social Theory to IS research	38
2.3	Summary of theoretical concepts used in this case study	40
3.1	National data items for child (under 5 years) health, 2002	58
3.2	National indicators for child health (existing and revised)	59
4.1	Major milestones and activities in TDCSP	75
4.2	Participatory evaluation and situation assessments conducted in the child-health intervention	76
4.3	Research method by municipality	78
4.4	Number of participants by municipality	79
4.5	Dates of fieldwork	80
4.6	Examples of groupings for the definition of 'well-being'	82
5.1	Health facilities in UThukela District by municipality	98
5.2	Context pre-1994	112
5.3	Context post-1994	113
6.1	Meaning of 'at-risk'	126
6.2	Meaning of 'well-being'	127
6.3	Conditions for 'well-being' and 'at-risk'	128

6.4	<i>Izinkomba</i> ('measures') of 'at-risk' and 'well-being'	130
6.5	Community Health Worker response on how to measure community indicators	138
7.1	Developing the community indicators	141
8.1	Rethinking participation and challenges to be addressed	170
9.1	Criteria, positive influences and potential distortions in striving for the 'Ideal Speech Situation'	189
10.1	Monitoring and Evaluation: Human rights implications compared to sustainable livelihoods principles	196
10.2	Category and types of generalisations	208
10.3	Generalisations from the UThukela District case study	210
10.4	Theoretical contributions of research	211

Part I

Setting the Stage

Chapter 1

Problem addressed and background

This chapter outlines the purpose of the research and the problems that this research addresses. It looks briefly at the constitutive and legislative framework in relation to children in South Africa and how child health status is captured in the existing Health Information Systems (HIS). Given the gaps of community-based data, and the increasing number of children living in vulnerable situations in the country, the argument is made for the need for a child-health Community-Based Information System (CBIS). By way of establishing the background and context of the location for the research, a brief description of the OKhahlamba Municipality in the UThukela District is given. This chapter concludes with an outline of this thesis and the logic to the framework which I adopted.

1.1 Introduction

Historically in South Africa, the District Health System (DHS), and consequently the District Health Information System (DHIS), was designed to serve the political agenda of the apartheid government. This approach was further exacerbated by the deeply fragmented health system which strengthened the formation of a culture of distrust in the Health Information System (HIS). Even though achievements have been made since 1994 in the area of HIS, the existing DHIS in South Africa is still primarily a facility DHIS. Consequently, only those who access health services through these facilities are included in the system. Community-Based Information Systems (CBIS) are virtually non-existent. With the impact of HIV/AIDS and increasing poverty, children have increasingly become a more vulnerable and further marginalised group. Many of these children do not access the basic health and social services and are thus excluded from the HIS. Policy and resource decisions made by the district, based on current health facility information, inadvertently or advertently, reinforce the exclusion of these already-marginalised children.

1.1.1 Absence of Child-Health Community-Based Information Systems

In *Children on the Front Line* [UNICEF, 1989] it is mentioned that the statistical information which a society chooses to collect or to ignore about itself, tells one a great deal about the priorities and power relations within that society. In the past, South Africa developed three different ways of 'making itself not to know' about uncomfortable truths.

The first way is the simple procedure of not collecting the data. Statistics on the infant mortality rates of white, 'coloured', and Asian babies are carefully gathered but there is no systematic measurement of the mortality of African children.

The second way is the process of discouraging people from reporting embarrassing facts. By removing kwashiorkor from the list of 'notifiable' diseases in 1968, the Government removed the legal obligation on the medical profession to inform the authorities of all such cases.

The third way is the declaration of certain areas to be invisible for the

purposes of gathering national statistics. Thus, for example, the creation of 'black national states' out of the impoverished rural reserves of the Transkei, Ciskei, Bophuthatswana and Venda in the five years after 1976, did wonders for South Africa's tuberculosis figures. [UNICEF, 1989, p. 69]

Though the IS in South Africa has changed, the above example clearly illustrates that IS design is largely a political process. Most systems are designed to uphold the dominant view of society in terms of what information is to be collected, how it is collected and for whom it is collected. Using an IS to create a particular picture of a situation is not uncommon practice as, though in relation to the sociology of record keeping, Becker notes that

... keeping records is a commonplace activity in most contemporary organisations; to understand how the organisations work you have to know how the records are kept. But knowing that means that you know too much to take them as accurate sources of information for social science purposes. [Becker, 1998, p. 102/103]

He further requests researchers, when examining already collated data, to critically reflect on where the data comes from, who gathers it and what the organisational and conceptual constraints faced are.

In relation to HIS, the health system in South Africa was historically, and to a certain extent still is, extremely fragmented. The HIS was fragmented vertically by race and horizontally by type of service. Additionally, there was geographical fragmentation in each of the homelands [Braa and Hedberg, 2002, p. 136]. Until May 1994 there were fourteen Departments of Health at central level and a corresponding number of HIS. Due to this fragmentation, decision makers learned not to rely on data for decision-making as there was little confidence in the IS. The data was often inaccurate in that data elements were not always defined in the same way for all the Departments. Aggregation was often not possible and comparisons across facilities and over time could not be made. Given the sheer number of reporting units, reporting was incomplete and/or out of date. It also made comparisons very difficult and meant that the disparities within South Africa were hidden.

Much has been done in the area of HIS since 1994. The National Health Information Systems of South Africa (NHISSA) committee was established and progress

has been made in the development of the facility DHIS. However, exclusion still exists. The main shortfalls of HIS in South Africa today are the exclusion from the IS of people who do not access the health services and the lack of data generated that is utilised for action.

Appropriate formal CBIS are virtually non-existent. Though information from the community is viewed as being important in terms of developing a comprehensive DHIS, the current DHIS largely excludes any information on what is happening outside of the health facility. The system needs to be expanded to include the geographical population and not just those accessing the health facility services. This will necessitate integration and the linking of IS, from different levels and sectors, so that a comprehensive DHIS can be achieved.

The rationale of this research is that vulnerability of children can be tackled using two interconnected strategies. The first is through the creation of awareness and visibility of the situation of children and the second through mobilising the commitment and action of government and society to address this situation by acting effectively on the information being produced. These strategies can be supported by designing an IS for action - an IS that can be used for advocating and influencing decisions and policies for the rights of these children. This research contributes, on a practical level, to the development of a child-health CBIS which was designed to create this awareness of the situation of children in the community. It explores how this system can be linked with information flows at higher levels and affect these higher level health structures. It explores how IS design, from a human rights and developmental perspective, can be used as a tool for community development and contributes on a theoretical level to rethinking processes of participation and communication in IS design. The commitment of the Government of South Africa is elaborated upon in the constitution and legislative framework. This commitment is discussed briefly in the next section.

1.1.2 Constitution and legislative framework for children

The Government of South Africa has an impressive constitution and legislation to support children's rights, which includes the right to basic health-care services [Government of South Africa, Chapter 2, 28:1:c]. The government and various Non-Government Organisations (NGO's) have adopted the principle of a 'first call for children'. This commitment is reflected in:

- the statement that the needs of children must be paramount throughout the Reconstruction and Development Programme;
- the acceptance of the World Summit goals for the survival, protection and development of children, which has been adapted to South African needs;
- the establishment of an inter-ministerial committee to guide the development of a National Programme of Action (NPA) for children;
- the ratification of the Convention on the Rights of the Child (CRC) in 1995;
- the approval of the NPA framework and its implementation by relevant government departments in 1996 (the commitment of the Government of South Africa to the NPA is reflected by the movement of the NPA Cabinet Committee in April 1998 to the Office of the Deputy President), and;
- the constitution established that 'a child's best interests are of paramount importance in every matter concerning the child'. [Government of South Africa, Chapter 2, 28:2]

The government's commitment is, therefore, legislated and the government also holds the view that the community is important in ensuring that this commitment is honoured. One of the priorities of the government is for community participation which is apparent since the early days of the Reconstruction and Development Program (RDP) and is enshrined in the constitution and local government legislation. There is also the recognition for the need to bridge the gap between service providers, whether they are the local government authorities or the respective government departments, and the communities they serve. Communities and service providers need to share relevant information on the local situation in order to develop and prioritise strategies that will improve the situation. Sharing respectful dialogue and resources between communities and service providers can produce positive and lasting improvements by creating a shared vision, goal and objective through approaches that foster equity and shared responsibility.

1.1.3 Child-Health Information Systems

If we are to create an accurate picture of the status of children's health and monitor the government's commitment to children, an IS that includes children and measures their vulnerability is essential. Through the development of the DHIS, each province has developed a minimum data set that contains data items that all Primary Health Care (PHC) facilities are expected to collect and forward to district level on a routine

basis. The data items relating to child health (under 5 years), in the minimum data set and in the indicators calculated, are given in Chapter 3, Section 3.5.1. Significant progress in increasing the number of data items and indicators in relation to children, which have standardised definitions amongst health and IS staff, has been made in recent years. For example, in 2000, all provinces were collecting only two common data items in relation to child health (immunisation coverage under 1 year (annualised) and diarrhoea incidence under 5 years) [Bamford and Chopra, 2001, p. 28]. In 2003 all provinces are collecting the standard minimum data set, relating to children, of 18 items. Furthermore, definitions used by the health workers in the classification of childhood illnesses and definitions used in the HIS are being standardised, for example, incidence of diarrhoea under 5 with dehydration and with no dehydration. Attention is being drawn increasingly to the use of such data.

If we are to measure children's vulnerability in a country with a devastating AIDS pandemic, some account of HIV/AIDS incidence would seem to be appropriate. Even though survey data is unreliable in relation to HIV/AIDS it can be said, with some authority, that there is an increasing number of children in distress as a result of the HIV/AIDS epidemic. From the rapid appraisal of children living with HIV/AIDS in South Africa, children in distress, comprise children infected (through mother-to-child transmission, sexual abuse and unsafe health practices) and affected (from households with infected family members) by HIV/AIDS [Smart, 2000, p. 20/21]. Barnett and Whiteside argue that

AIDS affected households tend to be poorer, consuming less food and with smaller disposable incomes; it is hardly surprising that children in these households are usually less well nourished and have a greater chance of being stunted or wasted. (quoted in [Giese et al., 2003, p. 50])

Vulnerability is certainly exacerbated by the pandemic, but HIV/AIDS is not the sole cause of vulnerability. In a study assessing the health and social services capacity to address the needs of orphans and other vulnerable children in the context of HIV/AIDS in South Africa [Giese et al., 2003], the researchers noted that most research participants located vulnerability firmly within a broader context of poverty and difficulty, arguing that children living in poverty-stricken, HIV/AIDS-affected communities are all vulnerable. As Giese, Meintjes, Croke and Chamberlain note

Rather than introducing specifically new patterns of social process relating to the care of children, it can be argued that the HIV/AIDS

pandemic is amplifying those that already exist in part, like the pandemic itself, as a result of economic and social fragmentation, deepening poverty, inequalities in urban and rural resource distribution, gender inequalities, cultural practice, and other material and social conditions. [Giese et al., 2003, p. 72]

Though we need to understand the causes of vulnerability in order to set priorities, trying to divide vulnerability into different categories based on different causes, does not address the fact that most of the causes of vulnerability overlap and co-exist. We cannot tackle only one aspect or cause and succeed in making children less vulnerable. Vulnerability is not static and children can move in and out of vulnerable states. It is important to understand the multiple reasons of children being in vulnerable states so that the process of vulnerability can be addressed.

So, simply having figures showing the number of orphans, or HIV incidence, is insufficient to paint a picture of children's vulnerability. The impact of HIV/AIDS contributes to this vulnerability, but children, orphaned by AIDS, do not constitute the only group of vulnerable children in South Africa. Further, through their life cycle, children may move in and out of various categories of vulnerability, as their circumstances change. Vulnerability is not a state of being, but a continuum - a pathway that can be taken and exited from as the context changes. Not only are there gaps in the data on the situation of vulnerable children in South Africa, but there are also gaps in our understanding of the term 'vulnerability', of what vulnerability means to communities and to the children. To include the term 'vulnerability' in an IS requires defining it, and it is this process of defining it that is further investigated in this research in the UThukela District in KwaZulu-Natal.

1.2 The case study

In relation to health services after 1994 the South African Government gave top priority to using the PHC approach in the delivery of health services, emphasising the need to serve the community, as well as recognising the importance of community participation in the delivery of those services. Based on these principles, in 1997, the National Department of Health adopted a new strategy regarding the care of children under five years. This new strategy, under the label of 'Integrated Management of Childhood Illnesses' (IMCI), has the overall aim of reducing mortality

and morbidity due to common diseases, and thus improving the life and welfare of the under five child in South Africa. As part of this strategy there was still the need for an IS that would support the creation of increased awareness of the situation of children and enable improved monitoring of that situation. This IS would primarily assist community members in their decision-making and care of their children.

In 1999, the UThukela District Child Survival Project (TDCSP - herein referred to as the Project) was selected, by the National Department of Health, as one of three learning sites for the development of a community component to the child-health intervention. The design of the child-health CBIS was part of this intervention. The Project is a NGO that initially operated in the OKhahlamba Municipality from 1995 to 1999 and expanded to the rest of the District from 1999 to 2003. Through a partnership with the community and Department of Health, the Project's mission, during the eight years of operation, was to create a well-being context through child health, maternal health and HIV/AIDS interventions which were co-designed and implemented in a holistic, integrated and sustainable manner.

In developing a community monitoring framework and IS, the Project relied heavily on its strategies of participation and capacity development. Two sites were chosen in this largely rural farming community - Loskop in the EMthezi Municipality, and Mazizini, in the OKhahlamba Municipality. The major difference between the two areas, at the commencement of the intervention, was that Mazizini had community health workers, while Injisuthi had none. In 2002, Community Health Workers were appointed in the EMthezi Municipality as part of a provincial commitment to the Community Health Worker programme. As the IMCI community component had been piloted in the OKhahlamba/EMtshezi Municipalities and the monitoring and evaluation framework was to be part of that pilot, most of the fieldwork was centred around these areas.

The UThukela District, like many other districts in South Africa in contemporary times, experienced significant processes of change with the restructuring of the health system. Initially, OKhahlamba and EMtshezi were districts in their own right. They, along with another district, have been amalgamated to form the UThukela District. Consequently, as IMCI was to be expanded into all Municipalities of UThukela District, some of the fieldwork was also conducted in the EMnambithi and ENdaka Municipalities. In addition to some name changes in the reorganisation process, regions became districts, districts became sub-districts

and finally, municipalities. The 'old' Bergville District became a sub-district in the interim phase and is now called the OKhahlamba Municipality, which is one of 5 municipalities in the UThukela District. The other 4 municipalities are now known as EMtshezi and EMbabazane, which are the 'old' Estcourt/EMtshezi Sub-District, and EMnambithi and ENdaka which are the 'old' Ladysmith/EMnambithi Sub-District (see Table 1.1 and the map illustrated in Figure 1.1, Source: [Ijumba et al., 2002, p. 498]).

Initial name (1994-2000)	Interim names (2000-2002)	Current names (2002 onwards)
Bergville District	Bergville Sub-District	OKhahlamba Municipality (KZN235)
Estcourt District	Estcourt/EMtshezi Sub-District	EMbabazane Municipality (KZN236) EMtshezi Municipality (KZN234)
Ladysmith District	Ladysmith/EMnambithi Sub-District	ENdaka Municipality (KZN233) EMnambithi Municipality (KZN232)

Table 1.1: Changes in names of the case study area

In order to understand the context in which the IS is to be designed and developed, it is important, particularly when using an interpretive perspective, to understand the broader context - not just related to the IS, but also in the lives of the people to be represented by the IS. The next section gives a brief picture of the OKhahlamba Municipality.

1.2.1 Physical and demographic conditions

The UThukela District lies in KwaZulu-Natal on the eastern coast of South Africa. This mainly rural, agricultural region is approximately 200km west of Durban, and 370km south of Johannesburg and consists of mostly mountains and grassland, producing cereal crops, beef and dairy. The District is also the catchment area for the Thukela River. Its boundaries are marked by the Northern Drakensberg Mountain Range in the south, which separates it from Lesotho, and the Free State Province in the west. The District covers an area of 11 252 km², with a population density of 54/km² [Ijumba et al., 2002].

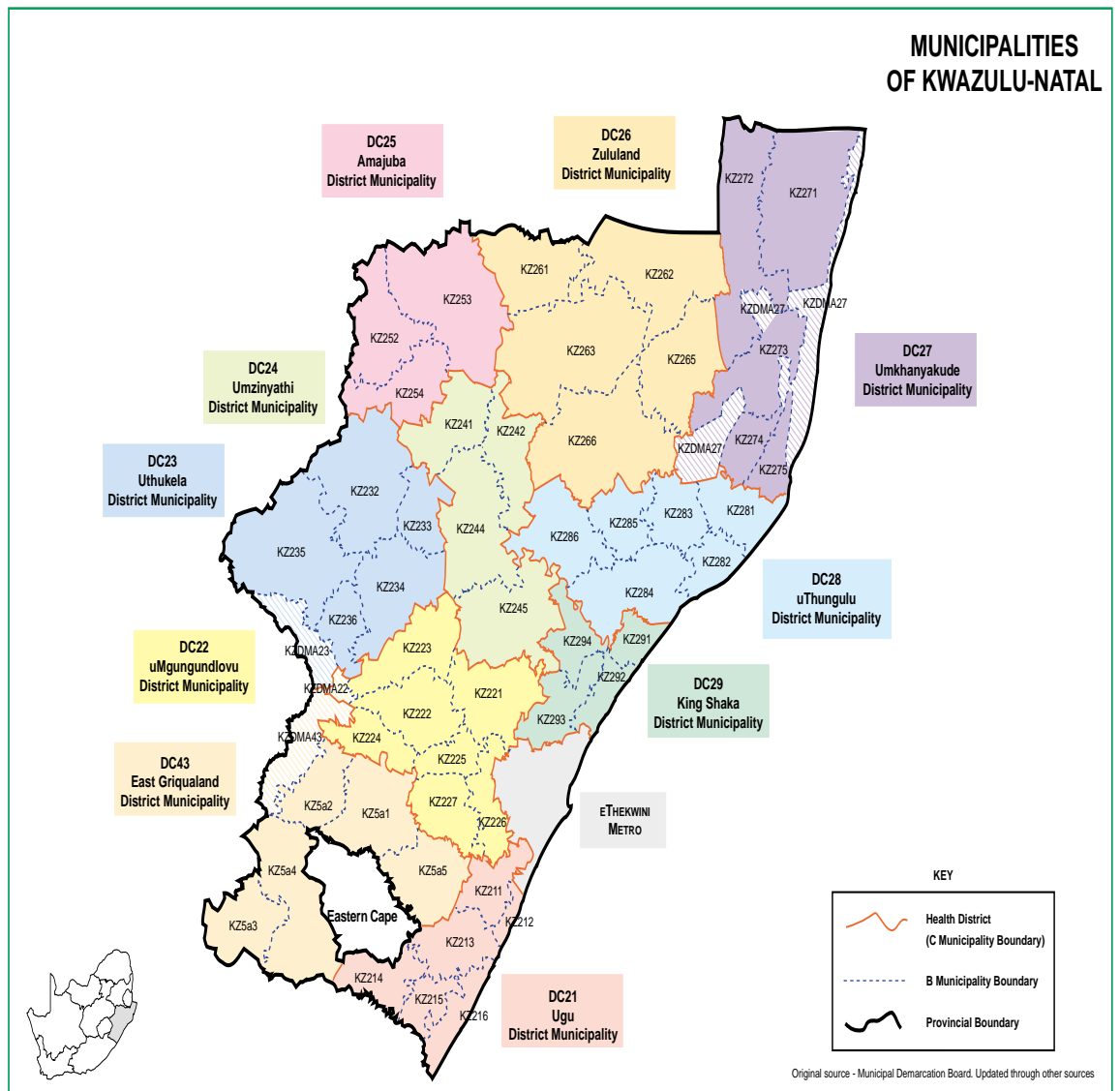


Figure 1.1: Municipalities of KwaZulu-Natal

The UThukela District is home to about 608 000 people living in 155 communities (*isgodi's*) (see Table 1.2, Source: [Ijumba et al., 2002, p. 499]). The population in the District is mostly rural and poor. The majority of people live on tribal lands (80%), freehold land areas (10%) and on commercial farms (10%). In the Project areas, people live mostly in scattered homesteads under the tribal system of government and the local government processes. Some subsistence farming is practised. Households are geographically widely spread with families sharing homesteads, but having no central village point.

Municipality	Population
EMbabazane	122 932
EMtshezi	51 709
ENdaka	107 819
EMnambithi	195 435
OKhahlamba	130 157
Total	608 052

Table 1.2: Population of UThukela District by Municipality

1.2.2 Socio-economic status

KwaZulu-Natal is among the poorest provinces in the country in terms of poverty rates, with 59.3% of children living in poor households. This province has been identified as having the highest 'deprivation index' of all nine provinces, or being home to about 24% of the country's most severely 'deprived'. This index is a composite of twelve indicators of deprivation, namely the absence or inadequacy of the following: education, income, wealth (assets), housing, water, sanitation, energy, employment, transport, nutrition, health-care, and perceived well-being [Government Communications, GCIS].

Mean income levels are judged to be below subsistence levels for South Africa. Access to fuel, transport and communication services is poor, but improving. Transport is often a problem during the summer rains when rivers become impassable, and roads and bridges are sometimes washed away. The government has made significant progress in electrification and road improvement, but there are few job opportunities for local inhabitants. Historically, due to the forced removals of Africans to land which is of low productivity, men formed the large pool of labour required

for South African business. The imposition of a land tax, which was payable in cash, forced many men to leave their families in order to earn a wage. The OKhlahlamba Municipality is no different to many other rural South African areas where nearly half of the economically-active men in the area became migrant workers. Many able-bodied persons have migrated to urban areas, causing the population to be largely female, young or elderly. Increasingly, young women have joined the urban-pull, leaving their children in the care of the grandmothers. Migrant labour has high risks when it comes to the spread of HIV and has contributed significantly to family disruption.

Access to land and the land tenure system also contributed, and continues to contribute significantly to poverty in the District. The UThukela District is 11 252km² in extent, with less than half of this land allocated to Africans who form 97% of the population. Ninety five per cent of the land occupied by Africans is tribally owned and divided between two major sub-tribes of the Zulu people; the Amangwane tribe, comprising 75% of the population, and the Amazizi tribe, comprising the remaining 25%. Except for two small towns, Winterton and Bergville, the area is essentially rural. Africans were denied the right and financial means to purchase land under the Land Acts of 1913 and 1936. As a result, 93.6% of the African population has an average of 1.4 hectares per family in the uThukela area, which is substantially lower than the 4 hectares necessary for viable subsistence farming in the area [Bergville District Child Survival Project, 1996a]. Due to overcrowding and a lack of extension services, agriculture contributed a mere 11.7% towards household income in the area [Bergville District Child Survival Project, 1996a]. Dagga (Marijuana) cultivation has become a lucrative, though illegal, source of income from the land.

Traditionally, communal land was allocated to men only and private property was defined legally, in such a way, to exclude women [Beinart, 1987, p. 302/3]. Economically, the imposition of the hut tax, under the apartheid regime, led to forced migration to the urban centres for work, as the land Africans were allocated was not agriculturally viable. This, in turn, disrupted family life [Cloete, 1979, p. 21]. Access to land was also largely dependent on women's relationship with men. Many rural women were accordingly landless, perpetual minors and dependent on their husband's family [UNICEF and NCRC, 1993, p. 89]. In practice, during colonial times, widows, or women left behind by men in town, were able to secure

significant rights over land. In some cases, land was held in their name, even if one of their male kin was the recognised taxpayer for it. Alternatively, the land might be held in the name of the male heir, but effective control was exercised by the mother [Beinart, 1987, p. 334]. Migration also changed some traditional practices. Women were generally not allowed into the cattle byre, in the homestead, as this was viewed as a sacred area. However, with migration, many women were forced to take responsibility for the livestock and so this practice changed [Magubane, 1998, p. 40].

National figures for unemployment have risen from 23.3% in 1999 to 29.4% in 2002 [Ijumba et al., 2002]. The unemployment figure, over the same period, for KwaZulu-Natal is 25.9% and 34.3% respectively [Ijumba et al., 2002]. Amongst the employed people, there are a large number of migrant workers. Within the Project areas, there are relatively few job opportunities. A survey carried out by the then Bergville Child Survival Project in 1996, revealed the following sources of income [Bergville District Child Survival Project, 1996b] for families:

41.9%	salary/wages
24.5%	pensions
16.8%	remittances
11.7%	home-based income
5.7%	income from own business

Table 1.3: Sources of income

A Knowledge, Practice and Coverage (KPC) survey, undertaken in the OKhlahlamba Sub-District, again by the Bergville District Child Survival Project, in 1999 [Bergville District Child Survival Project, 1999b], asked questions about the income-generating activities of the mothers in the survey and are shown in Table 1.4. A survey in 1996 showed that 74% of mothers had no income-generating activities, indicating that this figure has risen by about 8% [Bergville District Child Survival Project, 1996b].

Unemployment amongst the youth is particularly problematic. Apartheid hindered black urbanisation and prohibited the majority black population from becoming entrepreneurs. Additionally, Africans were systematically deprived of access to education, skills and the experience essential for the emergence of entrepreneurs, especially informational skills. It is often postulated that this leads to youth en-

82.3%	no income generating work
8.1%	hawkers
5%	handicrafts
1.7%	casual labourers
1%	sell home-prepared foods
0.3%	domestic workers
0.3%	shopkeepers

Table 1.4: Income-generating activities

gaging in high risk behaviours. The reason for this is that they do not have a sense of purpose in life and have no future plans, and therefore, have nothing to lose in the future by engaging in high risk behaviour in the present [Mathur et al., 2001] [Pleck et al., 1990]. It is 'the culture of urgency' - the idea that there is no future, no roots, only the present [Castells, 2000a, p. 164]. However, in a recent survey in South Africa [Pettifor et al., 2004] when youth (15-24 year olds) were asked how they feel about their future opportunities to be successful and prosper, 72% of youth reported that their opportunities were limitless or that they had many opportunities.

Poverty is not confined to any one race group, but is concentrated among black Africans. There are also disparities between children living in rural areas, who are more likely to be poor, than those in urban centres. Poor children suffer and die from diseases that could easily be prevented by improving basic health conditions and access to water and sanitation services. Nationally, infant mortality rates have been estimated at 59/1000, and under-5 childhood mortality 100/1000 [Ijumba et al., 2002]. For KwaZulu-Natal, the estimates are 68/1000 and 124/1000 respectively [Ijumba et al., 2002].

On the positive side, the national literacy rate is 85.9%, while literacy for KwaZulu-Natal is 89.2% [Ijumba et al., 2002]. In the KPC in Okhahlamba Sub-District, literacy among women with children under 2 years was 81% (69% in 1996), 11.3% had no formal education, 8% had been to primary school, but couldn't read, 21.7% had been to primary school and could read and 59% had been to secondary school or higher [Bergville District Child Survival Project, 1999b]. This implies that, in the Project area, most mothers are functionally literate.

1.2.3 Health status

Important indicators of human development are health indicators. In South Africa, child health indicators point to the lingering effects of apartheid's racial, geographic and socio-economic policies. From the following figures (see Table 1.5, Source: [Ijumba et al., 2002]) the indicators for child-health status indicates that KwaZulu-Natal is worse off than the country as a whole.

Indictor	South Africa	KwaZulu Natal
Infant mortality rate (2002) (per 1000 live births)	59	68
Under 5 mortality rate (2002) (per 1000 live births)	100	124
Immunisation coverage of children 12-23mths (1998) (%)	63.4	49,5
Diarrhoea incidence under 5yrs (2002) (per 1000)	133.4	211.5
Neonatal mortality (1998) (per 1000)	19.8	23.2

Table 1.5: Child Health Statistics

In 1999 the average neonatal mortality rate was 22/1000 live births for babies born in facilities in OKhahlamba/EMtshezi Municipalities (it was as high as 40/1000 in March 1999). The actual number of deaths may be slightly higher in reality as deaths of newborns delivered at home are often not registered. The Infant Mortality Rate and under 5 mortality rate are unavailable for the District.

One of the main concerns for OKhahlamba Municipality is HIV/AIDS. South Africa is regarded as having one of the highest HIV prevalence rates in the world [Department of Health, 2002]. In 2002, the National Department of Health undertook the thirteenth in a series of annual sentinel HIV prevalence surveys conducted among pregnant women attending antenatal clinics in the public sector. KwaZulu-Natal's HIV infection rate is the highest of all provinces in South Africa, with 36.5% of women attending antenatal clinics testing positive for HIV in 2002 (it was 33.5% in 2001), as opposed to the national figure of 26.5%. Women in their twenties (25-29 years) have the highest rate of HIV infection nationally, but between 2001 and 2002 the HIV prevalence increased from 31.4% to 34.5%. With high teenage fertility rates this picture is unlikely to change in the near future. In 1998, the provincial fertility rate for KwaZulu-Natal was 3.3%, and the provincial teenage

pregnancy rate was 13.8%. In OKhahlamba/EMtshezi Municipalities the average teenage pregnancy rate for young women delivering in facilities in 1999 was 22.9%, significantly higher than the provincial rate. The actual rate may be higher, as at-home deliveries (which are common) are not included in this figure.

As the antenatal survey is a proxy indicator for the development of the HIV epidemic in the general population, a study to augment the National Department of Health annual HIV prevalence surveys was conducted through a population-based sample in 2002 [HSRC]. Contrary to the HIV prevalence survey conducted by the Department of Health this survey reports that KwaZulu-Natal ranks fourth in terms of prevalence rates (11.7%). Free State, Gauteng and Mpumalanga Provinces are the highest with prevalence rates of 14.9%, 14.7% and 14.1% respectively. The overall prevalence for the country is 11.4% for all age groups, geographic areas and race groups. Incidence is still highest in the 25-29 year old age group (28.4%)¹ [HSRC].

In the Human Sciences Research Council (HSRC) survey it was found that HIV/AIDS affects all race groups in South Africa.

The differences are largely due to social, economic and behavioural determinants, such as living in informal settlements, being poor, having access to information and education necessary for prevention, knowing people who have HIV/AIDS or died due to AIDS, having multiple partnerships, as well as having STI's (sexually transmitted infections). [HSRC, Executive summary, p. 19]

Women have higher HIV prevalence than men. There are biological and social reasons for this. Women's reproductive systems make it easier for them to be infected with HIV, whilst men are more effective at transmitting the virus. On the social side women, through the existing patriarchal social system, factors which put women particularly at risk from HIV/AIDS are: sexual subservience to men; time consuming workload, usually involving the care of children, which makes access to health services difficult; higher risk of transmission with migrant labour partners; differential access to information and resources for prevention; women's economic

¹The report notes several possible reasons for the discrepancies in Provincial prevalence rates. In KwaZulu-Natal many of the antenatal sentinel sites are along national or main roads and transport routes are known to contribute to higher levels of HIV prevalence. The HSRC study sampled respondents from urban and rural areas throughout KwaZulu-Natal [HSRC].

situation; deep-seated acceptance, if not actual encouragement, of multiple sexual partners for men and, women often remain with spouses who are HIV positive rather than vice-versa.

Children are particularly susceptible to the ravages of the HIV/AIDS pandemic. There is a high rate of mother-to-child transmission either through delivery or through breastfeeding. There are also an increasing number of AIDS orphans and consequent child-headed households.

The higher risk of HIV infection for women is combined with the already precarious position of women in KwaZulu-Natal. Women (mothers, grandmothers and older girl children) are predominantly responsible for childcare. The final Knowledge Practice and Coverage (KPC) survey [Bergville District Child Survival Project, 1999b] for the Bergville District Child Survival Project showed that when mothers are working away from home and do not take children with them, grandmothers take care of the children in 60% of cases. Older children are the next choice for childcare (in about 8% of cases), with 'other relations' following at about 6%. Friends and neighbours also occasionally provide childcare (4%).

Poorer children, living in rural areas, have poorer access to PHC facilities than children living in the wealthier, more urbanised, areas. They have greater distances to walk and fewer health personnel to cater for their needs. KwaZulu-Natal is one of two provinces with especially poor client-to-clinic ratios (23,000 clients per clinic) and in 1995, only 54.3% of households in KwaZulu-Natal (nationally this was 62.2%) were within 5 kms of medical care, the second lowest in the country [Robinson and Sadan, 1999].

This situation is exacerbated by disparities in access to basic infrastructure. Access to potable (drinkable) water and sanitation are often critical to improving child health outcomes. The government has, however, committed itself to improving access to water and sanitation. In spite of two major dams and several springs in the area, a serious shortage of water for agriculture and clean drinking water has impacted nearly every household, and influenced the health status of the area. The cholera epidemic in 2001 is evidence of this poor access. In KwaZulu-Natal the percentage of the population with a toilet, in 1996, was 39.8% compared to 44.7% nationally (though, nationally, this figure rose to 52.7% in 1999, but there is no comparable figure for KwaZulu-Natal) [Ijumba et al., 2002]. In 1999, 34.6% of the population had piped water in the province inside the home, which was close to

the national figure of 38.7% [Ijumba et al., 2002]. A situational analysis for the OKhahlamba Municipality, completed in July 1998, estimates that only 25% of the population live within 15 minutes walking distance of safe water, and only 25% have adequate sanitary facilities, indicating gross disparities not only within the country but also within the province. Transport remains poor, particularly during rains when rivers become impassable [Bergville District Child Survival Project, 1999b].

There are a reasonable number of health facilities in the District (33 clinics, 23 mobile points and 3 hospitals for a population of just over 600,000). However, in some areas, distances of over 10km have to be travelled in order to access these services. Furthermore, especially for maternal health-care, access to 24 hour health facilities is limited. This is further compounded by having the second lowest emergency response rate of clinics in less than one hour in the country, though significant improvement (from 29% to 55.3%) has been made between 1998 and 2000 (nationally this is 55% and 57.5% for the same period).

1.3 Conclusion

Children move in and out of states of vulnerability throughout their lives. OKhahlamba Municipality is no different in this respect to the rest of South Africa. IS design and development can highlight and monitor the process of vulnerability in a country like South Africa where commitment to children is constitutively and legislatively strong. An IS can help communities advocate for, and demand, the realisation of this commitment. The current HIS in South Africa does not include the measurement of vulnerability of children. This needs to be contextually developed. As OKhahlamba Municipality had already been selected as a pilot site for the community child-health strategy, IMCI, this was the site selected for the research to take place on how to design and develop a child-health CBIS.

The need for the child-health CBIS had also been requested by the community members of OKhahlamba Municipality. One of the outcomes of a participatory monitoring and evaluation workshop (February 2000) was the request of community members for assistance in designing an IS that would enable them to monitor the situation of their children. The absence of an appropriate child-health CBIS was endorsed by the findings of the DHIS review [TDCSP, 2001] and a participatory situational assessment of child health [Gibson et al., 1999]. Key aspects of the

process, participation and communication, were seen to be fundamental to the design and development of the system. Each of these themes is elaborated on in subsequent chapters, but, before discussing these themes, I complete the 'setting of the stage' in the following chapters and conclude this chapter with an overview of the rest of the thesis.

1.4 Overview of thesis

The thesis is structured in four parts:

- Part I 'sets the stage' and has begun here with this introductory chapter on the statement of the problem - the absence of a child-health CBIS that addresses vulnerability of children. The next component of 'setting the stage' is given in chapter two where the theoretical perspective is outlined. This explores how concepts of human rights, participation and capacity development developed throughout the research process and how aspects of specific theories, namely Structuration Theory and Critical Social Theory, lend insight into the situation under review. I continue, in chapter three, to explain what is meant by the term 'vulnerability' in this research and how, through IS design, vulnerability can be attempted to be addressed. To complete the background, a brief overview of the HIS in South Africa is given. The research on developing the child-health CBIS is placed in that context and the research questions that this research addresses are outlined.
- Part II commences in chapter four with the formulation of the research problem and objectives. Fitting in with the theoretical framework used, the chapter concludes with a discussion and justification of the methodology employed. Using concepts from Structuration Theory, chapter five describes the social processes and changes in modalities which shaped the design process and outcome of the CBIS, in the UThukela District.
- Part III is a reflection on the process and output of the research. Using the participatory action research cycle each step of the process is described in chapter six. Chapter seven examines the output of this process and highlights the main changes which took place.

- Part IV looks at the analysis and implications of the research from both a practical and a theoretical viewpoint. Two concepts, participation and communication, are given particular attention. Chapter eight explores the role participation plays in the design of a child-health CBIS and the challenges faced in achieving optimal participation. Chapter nine looks at how, through communication, power structures within the design process were addressed and outlines the gaps still to be addressed in achieving the 'Ideal Speech Situation'. Chapter ten returns to the theoretical underpinnings of this research and outlines the main contributions made by this research to IS theory. Chapter eleven concludes the research with a focus on how this case experience in a localised setting can be integrated into broader level structures to effect longer institutional change on a practical footing and explores the challenges that still are faced in achieving this.

The framework is summarised in Figure 1.2.

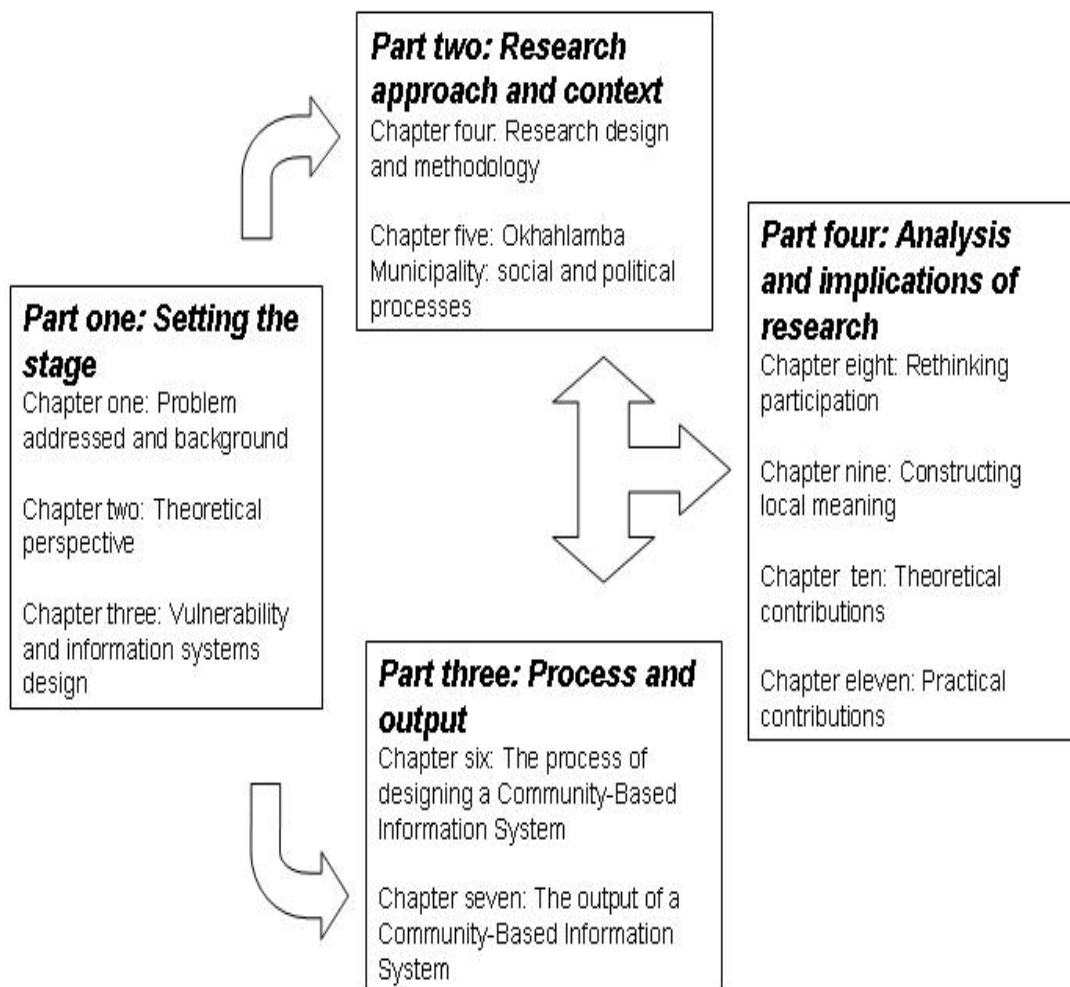


Figure 1.2: Outline of thesis

Chapter 2

Theoretical perspective

This chapter explores the insights gained and concepts used from two theories. Both theories referred to, Structuration Theory and Critical Social Theory, are social theories rather than IS theories per se. Both theories have been increasingly applied over the last decade to the IS field. This chapter explores how aspects of both theories influenced the analysis of design and development of the CBIS. Giddens' Structuration Theory provided insight into how structures are formed and in understanding the context. Habermas' Critical Social Theory and arguments for the creation of public sphere or 'Ideal Speech Situation' influenced both the methodological choices I made, and contributed to the rethinking of participation and communication in IS design. In addition, both theories influenced the output of the research in terms of information flows and communication loops and the importance of influencing broader structures due to the complexity of the health system.

2.1 Introduction

Rather than adopting the approach of accepting a 'correct' theory, a number of theoretical routes were followed in my research that explained better or highlighted interesting aspects of the situation under review [Walsham, 1993]. These theories were not predetermined from the outset, but increased in relevance as the case study evolved, my exposure to literature increased and similarities and linkages became apparent and were investigated further.

Initially, certain concepts and strategies, or principles, in developing a CBIS were agreed to by the research team which comprised representatives from the TDCSP staff, Department of Health, community leaders, community facilitators and myself. As the human rights approach underlies the overall child-health intervention similar principles were to be applied to IS design. This human-rights approach implies developing a system using participatory approaches in its design as well as in its implementation. The right not to participate was acknowledged, and people were to participate in the process only if they felt that it would help them in their day-to-day activities. This also implied that the design of a system needed to be context specific. Developing the capacity to participate, as well as the capacity to act based on the information received, was also an important strategy. Finally, the main objective in designing the IS was to enable a complete picture of child-health to be created and, from that picture, to improve the situation of children through advocacy, claiming rights or reflecting on previous, current and future action. Ultimately then, IS was viewed as a tool for the improvement of the health status of children.

Two theoretical roots, Structuration Theory and Critical Social Theory, fitted in with these concepts and strategies. The theories contributed substantially to guiding the research and assisted in adding clarity to the analysis of the research findings. This approach tried to balance the concern that "Theory is both a way of seeing and a way of not-seeing. A particular theoretical perspective blinds us to other perspectives at its moment of application." [Walsham, 1993, p. 6] and the fact that "Empirical research without theory produces a series of anecdotes" [Walsham, 1993, p. xiii]. The theories also allowed the principles of participation, capacity development and the importance of context to be highlighted and to form essential strategies in the design process.

In the following review of how I used Structuration Theory and Critical Social

Theory, cognisance was taken of the need to be true to the founding assumptions of these theories. In using concepts and ideas from the theories, I also attempted to place those aspects in the spirit of the original theory. In this chapter, I firstly outline how I used both theories to explore the context, the process of design and the output of the child-health CBIS. I then address the question of how this usage fits in with the contemporary debate in the IS field. Chapter 10 focuses on the theoretical contribution of this theory and how the use of theory in this research addresses some of the critiques of both theories.

2.2 Use of Structuration Theory and Critical Social Theory

In this section, I explore how both theories affected the analysis of the context in which the design was to take place, the process of design and the output of the research.

2.2.1 Context

Given that the IS to be designed was to assist in terms of human development, in particular improvements in the health status of children, I viewed IS design as a tool for emancipation and development. It is extremely important to explore the context within which that human development was to take place in terms of the structures which shape the IS design process, as well as how the IS design process can address the shaping and production of the structures. In explaining the context, there is the need to move beyond the vagueness in which the term 'context' is often used, or in using context as "an undifferentiated bath that warms the subjects of our studies" [Kling, 1991, p. 359]. It is in this respect that Structuration Theory is a very useful analytical tool. Exploring the context in terms of structures and its modalities, Structuration Theory not only allows us to recognise the need to challenge constraining structures, but also to build upon the enabling ones if changes in that context are to be made. Though there are many authors on structuration (for example, [Bourdieu, 1977] [Bhaskar, 1979]), Giddens' Structuration Theory is predominantly used in the IS field and is, therefore, used here.

Structuration Theory is set out by Giddens in three main works: *New Rules of*

Sociological Method (Giddens, 1976), *Central Problems in Social Theory* (Giddens, 1979) and *The Constitution of Society* (Giddens, 1984), and is also discussed in *A Contemporary Critique of Historical Materialism* (Giddens, 1981) (cited in [Jones, 1997, p. 104]). Giddens' Structuration Theory challenged the contemporary debate between the two major schools of sociological inquiry: those predominantly concerned with structure/objectivity and those concerned with agency/subjectivity. For Giddens', structuration is a social process that involves the interaction and reaction of people or human agents. The actions of human agents are formed by sets of rules, practices and routines which are developed over time in the minds of people. Actions produce and reproduce structures, but structures can also facilitate or constrain the actions of human agents. Thus, agents and structures are not seen as independent, but as a duality whereby structure is relied upon in human actions, and, in so doing, structures are produced or reproduced by those actions. The rules and resources drawn upon in action are simultaneously the means of system reproduction (this is what Giddens refers to as the 'duality of structure'). Structures are located in the minds of human actors, not in external constructions and can thus be changed or reinforced over time. The rules can be viewed as generalised procedures of action - those that exist 'in a social space' [Lyytinen and Ngwenyama, 1992]. Human agents are aware and knowledgeable of these rules, however, they cannot determine the outcome of their action, as action can have both intended and unintended outcomes. Structures can be facilitating or constraining to the actions of human agency, but are also formed through previous actions and reinforced through present action.

Actions are conditioned and formed by the context in which humans act. Human actors can change the situation they are in through action, but the participation of the collective action has greater potential to change or reconstruct the structures. In order to do this, they will need to act upon their knowledge and their capabilities to understand the existing structures that enable and constrain their development. Access to information is important for the development of this knowledge. Giddens breaks down social structure and human interaction into three dimensions which are interlinked by three modalities as illustrated in Figure 2.1 [Giddens, 1984].

To assist with the analysis of structure, it is useful to separate structure and interaction into these three dimensions, even though the dimensions are interlinked. As human actors communicate, they draw on interpretative schemes to help make

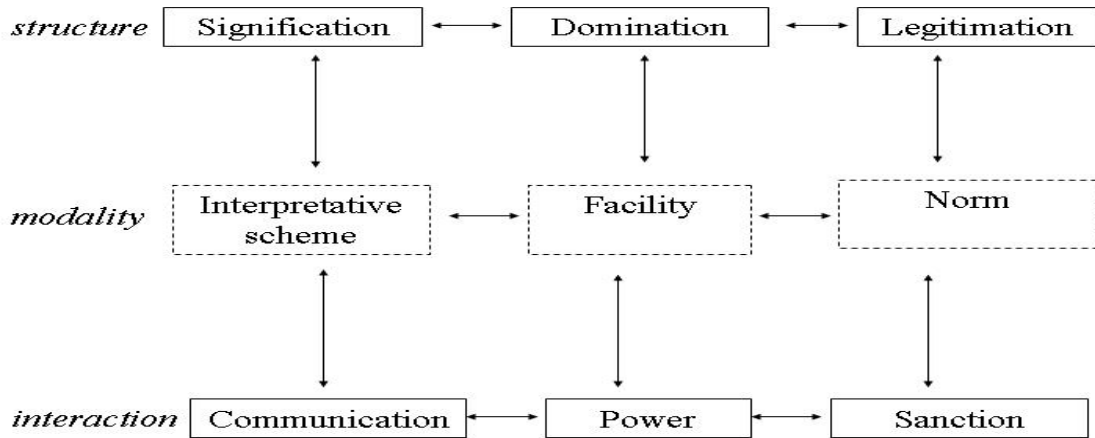


Figure 2.1: Dimensions of duality of structure

sense of interactions, whilst, at the same time, those interactions reproduce and modify those interpretative schemes. In a similar fashion, the facility to allocate resources is enacted in the use of power, and produces and reproduces social structures of domination. Facilities are the resources which actors can use in their actions. Material resources can be allocated by those who control them, but non-material resources, such as status, special skills, charisma, etc., may also be integral to action [Lyytinen and Ngwenyama, 1992, p. 23]. Moral codes (norms) help determine what can be sanctioned in human interaction, that is what is considered legitimate action [Rose, 1998, p. 4]. So if ”.. interpretative schemes are the rules for understanding what to know, norms can be understood as the rules for understanding how to act” [Whittaker, 2001, p. 138]. These structures are discursively and recursively formed and are therefore fluid. They demonstrate what Giddens terms a ’dialectic of control’ [Giddens, 1984, p. 16].

The design and use of IS are shaped by the very structures within which they are situated, but IS can also be used to help define and redefine these structures. By exploring each of the above dimensions of structuration in the process of IS design, IS design can be used as a tool for development by refining the structures to include the views and values of those currently disadvantaged by the existing structures. Through a participative and reflective process in IS design, cultural and traditional norms which influence human action can be explained, understood and

addressed which can influence legitimation. The design process, and the IS itself, can improve communication and encourage reflection, and change interpretative schemes and hence, structures of signification. Through the process of IS design and reflecting on the situation, the excluded can be empowered and this redefines power and how resources are allocated. This impacts on the structure of domination. In summary, IS design can be used to define and refine structures by understanding and incorporating all the dimensions of the duality of structure in the design process. Giddens' Structuration Theory allowed us to explore what constraining and enabling structures were already in place in the context under question.

Through changing and building on existing structures in IS design, the voices of the community can be heard and IS can be used as a tool for achieving their needs and the attainment of their rights. Habermas' Critical Social Theory [Habermas, 1987] fits in well with one of the objectives of this IS design - the changing of the context to one which would be better for children's health. Habermas believes that a theory of social action is required in the study of scientific knowledge and criticises the excessive focus on scienticism (or what he would refer to the excessive pursuit of the 'scientific methods' of the positivistic social theorists). In his book, *Theory and Practice*, Habermas maintains the argument of the Frankfurt School of the unity of theory and practice - the need for a dialectical social theory with practical intent [Kellner, 2004]. That is, theory and practice must be interconnected, as Critical Social Theorists seek to improve human condition. It is impossible to obtain this objective solely by critiquing ideology or theories and necessitates becoming involved in real life situations.

... the epistemological belief of the critical perspective is that knowledge is grounded in social and historical practices. There can be no theory-independent collection and interpretation of evidence to conclusively prove or disprove a theory. Because of the commitment to a processual view of phenomena, critical studies tend to be longitudinal. [Orlikowski and Baroudi, 1991, p. 20]

Critical Social Theorists have a fundamental belief that any social theory must view society and its constituent parts as dynamic [Lyytinen and Klein, 1985, p. 220]. Society can be changed by its members. Critical Social Theorists seek to emancipate people; they are concerned with finding alternatives to existing social conditions as well as challenging taken-for-granted conditions. In order to improve their condition

there is the need to become involved in a practical situation and to tackle issues of power and knowledge interests. The main goal is the improvement of the condition of peoples' lives. In my research, Critical Social Theory enables me to place the argument of improving conditions at a local level in a broader theoretical debate. This can take time and therefore a longitudinal approach is usually necessary and was adopted in this research.

As with Structuration Theory, in Critical Social Theory people are not viewed as passive receptacles of whatever data or information they receive, but are viewed as intelligent actors who assess the messages they receive. Furthermore, human actions are constrained or enabled by policies, norms, resources, power and authority, but there is the option to act, within limits, with or against those organisational and societal norms. People can change their material and social circumstances, as can researchers impact on the social setting they are researching. However, there is also the recognition that capacity to change is constrained "by prevailing systems of economic, political, and cultural authority" [Orlikowski and Baroudi, 1991, p. 19]. As such, an important objective of Critical Social Theory is to create awareness of these constraining factors so that people can make decisions on how to address them. As changes are made in these structures in a discursive manner the Habermasian sphere of public debate is a useful addition here.

Discourse is the medium of structuration. As structures are discursively and recursively produced, a particular dimension of structure is focused on in this case study - communication as an enabler as well as a constraint. Giddens [Giddens, 1984, p. 29] emphasises that it is communicative action that is sustained by, and sustains the structuring of signification, through interpretative schemes. In this research the debate over knowledgeable human actors and their ability to change the restraining structures occurs through the lens of Critical Social Theory, in particular Habermas' theory of communicative action.

Power is also a particular dimension that I focus on and how, through participation, this can be addressed. Giddens [Giddens, 1984] says the following:

Power is the capacity to achieve outcomes; whether or not these are connected to purely sectional interests is not germane to its definition. Power is not, as such, an obstacle to freedom or emancipation but is their very medium - although it would be foolish, of course, to ignore its constraining properties. [Giddens, 1984, p. 257]

So power can be constraining as well as enabling. As Walsham notes

The main messages are that power and its use in political activity pervade all action and discourse in organisations, that the exercise of power is a continuous process that has subtle local properties, and that local actions are linked in a complex way to more general networks and institutional frameworks. [Walsham, 1993, p. 40]

Information is an important element of that power.

2.2.2 Process of design

In contrast to traditional social theorists, Critical Social Theorists believe that researchers cannot be mere observers. They believe that, by their very presence, researchers influence and are influenced by the social and technological systems they are studying.

For Critical Social Theorists, the responsibility of a researcher in a social situation does not end with the development of sound explanations and understandings of it, but must extend to a critique of unjust and inequitable conditions of the situation from which people require emancipation. [Ngwenyama and Lee, 1997, p. 151]

This position influenced the methodology chosen. In this case study a participatory action research framework was used with a longitudinal interpretive approach where the iterative approach of implementing changes, evaluating the changes and making further changes and evaluations took place (see Chapter 4, Section 4.3).

Depending on the type of knowledge required, different types of action and inquiry facilitate the attainment of knowledge. In Critical Social Theory there are three types of social inquiry, related to Habermas' types of action: technical, practical and emancipatory [Ngwenyama and Lee, 1997] [MacIssac, 1996]. This is related closely to the three philosophical approaches: positivist, interpretivist and critical (see Chapter 4, Section 4.3.1). In Critical Social Theory, technical inquiry focuses on predicting and controlling the natural and social world. This type of inquiry is associated with the positivist school, the aim of which is to control the situation. Practical inquiry looks at human interaction and the context in which that action takes place. This type of inquiry is associated with the interpretivist school,

the aim of which is to understand the situation. Lastly, emancipatory inquiry focuses on the improvement of the human condition. This type of inquiry takes place through group discussion, where the force of the best argument has the ability to change a given situation. Critical Social Theorists acknowledge that all forms of knowledge are social constructions and "Each type of knowledge interest is believed to represent a frame of reference (or mental mode) through which researchers apprehend and make sense of the world as they seek to obtain knowledge about it." [Ngwenyama, 1991, p. 270/271] A critical interpretivist approach to this research is adopted in an attempt to understand the context before striving for emancipation and for changes in the health situation of children to occur.

Types of inquiry are related to types of action. Each type of action has a specific focus and orientation and, together, they represent different aspects of human behaviour in social settings. Ivanov employs an interesting phrase in describing this Critical Social Theory system as 'the design of conversation-negotiation systems' [Ivanov, 1991, p. 7].

The four types of action are:

- Instrumental action which is taken for attaining rational objectives. This action is taken when other agents are viewed as objects.
- Communicative action is concerned with achieving and maintaining mutual understanding. This action is taken to inform other actors of events or issues.
- Discursive action is taken when there is the need to resolve a disagreement. This action is taken when there is the need for joint action to resolve the situation.
- Strategic action is concerned with influencing and changing the action of others in line with the actor's desires or goals. Unlike instrumental action, other actors are treated as intelligent people.

Habermas' typology of action represents ideal types [McCarty, 1978]. It is an attempt to simplify complex social behaviours and to highlight their principal differences. The different forms of social interaction are summarised in Figure 2.2 which is adapted from Lyytinen and Klein [Lyytinen and Klein, 1985, p. 221]. Instrumental action is classified as a non-social form of interaction associated with the attainment of technical knowledge. Social action is broken into communicative and strategic action. The former, which takes place through language, is further divided into achieving mutual understanding and discursive action. Strategic action can be

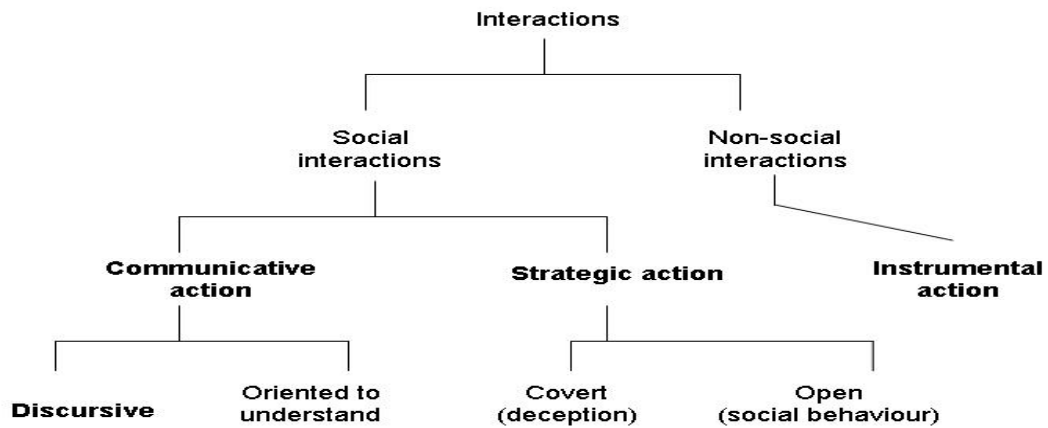


Figure 2.2: Social interaction in Habermas typology

open, such as social behaviour in market situations and covert behaviour, such as deception.

Habermas' debate on the creation of the public sphere and his later writings on communicative action influenced the direction of the approach taken in this case study in terms of how participation and communication were analysed and viewed. Two important aspects of Habermas' 'public sphere' are participation and the creation of a number of forums or public places of discussion. For Habermas, the success of the public sphere was founded on rational-critical discourse, where everyone is an equal participant and the supreme communication skill is the power of the better argument. Communication is the means of not just finding out what individuals have previously decided or learned, but a process in which opinion and consensus is created by the process of debate itself. In Habermas' theory of communicative action, all social action assumes a basic set of norms. Each act carries with it a set of validity claims. These validity claims concern truth, truthfulness, comprehensibility and normative right. Human actors are allowed to express themselves openly and freely and must accept the outcome of rational argument.

Habermas' theory of communicative action doesn't necessarily say that barriers to communication or action can necessarily be removed - this would mean that the 'Ideal Speech Situation' has been achieved. The main issue in his theory is the attainment of critical reflection of individuals, through which emancipation can

occur.

The underlying utopia is the emancipatory idea of a community of free and self-responsible citizens coming together and seeking to achieve consensus on matters of public (non-private) concern by means of argumentative, oppression-free will-formation and democratic majority vote. [Ivanov, 1991, p. 3]

Striving for the situation where people are free and open to discuss decisions formed an important part of my research. It involved the creation of various forums for discussion, as well as developing the capacity and expanding the experience of the people, and improving access, to participate in the forums. Additionally, for communicative action to occur, there is the need for a common understanding of terms, visions and cultural practices. Changes in the context of the case study in this research were made in terms of trying to develop a shared vision for children's health, agreement on action through various processes of reflection and learning, developing capacity and translations of common terms and concepts. How communication was addressed specifically using concepts from Habermas is described in detail in

2.2.3 Output

Structuration Theory can be used in analysing structures at many levels in an organisation and in society. In analysing the structuration process within the context of the case study most of the focus, in this research, took place at the community level. Given the complexity of the health system, however, many of the modalities for these structures at a lower level are affected by the structuration process occurring at levels above the local setting, such as province and national levels. Combined with the contemporary debate on the role of marginalisation and globalisation [Castells, 2000a] [Beck, 2000] [Giddens, 1991a] [Giddens, 1991b], it was important in this case study, in addressing vulnerability at a local level, to ensure that connections are made with the broader structures.

Globalisation has been accompanied by rising inequality [Madon and Sahay, 2002, p. 1] and increasing vulnerability. Castells [Castells, 2000a] refers to the groups of people affected by this inequality as 'the Fourth World', whether geographically located in the developed or developing world. These people and regions in the world are excluded from the economic flows associated with globalisation.

Castells [Castells, 2000a] explains how the structures in place in a global economy reinforce the exclusion of vulnerable people and how important it is to tackle this exclusion by ensuring that they are linked to the rest of the global market. Castells' arguments are drawn upon to connect with the broader structures in place in South Africa. Through changing information flows and communication loops, and using various media, information from the local level can be fed to the higher levels using the IS. Through participation and capacity development in the design process, reflection and discussion can take place at a local level and increase the chances of collective demands for their rights being realised. In the final chapters of this thesis (see Chapter 10 and Chapter 11), the broader question on how the experiences and findings of this research in the UThukela District can form part of larger structures, is addressed, from both a theoretical and practical perspective.

2.3 Application of theory in contemporary IS research vis-a-vis UThukela District case study

As mentioned, Structuration Theory and Critical Social Theory are social theories but have been increasingly used in the IS field. In this section, I briefly discuss this and demonstrate how this study contributes to this debate.

2.3.1 Contemporary application of Structuration Theory in information system research

Structuration Theory is a social theory and has been applied in many fields outside IS research, examples being organisational and management studies. The focus here is on how IS researchers have used Structuration Theory. Walsham and Han [Walsham and Han, 1991] analyse literature under topics of operational studies, meta-theory and specific concepts used. Jones [Jones, 1997] analyses the use of Structuration Theory in an attempt to reconstruct theory to accommodate technology. He further explores the application of the theory as an analytical tool, the use of theory as a meta-theory, and use of concepts from the theory. Rose [Rose, 1998] uses a categorisation of the literature on Structuration Theory in IS based on theorising, analysing and operationalising. The literature, based on Jones' [Jones, 1997] and Rose's [Rose, 1998] classification of how Structuration Theory has been

applied in IS, is summarised in Table 2.1.

Category	Use of theory	Examples:
Theorise	Reconstruct theory to accommodate technology	Orlikowski [Orlikowski, 1992] DeSanctis and Poole - GDSS Orlikowski and Robey [Orlikowski and Robey, 1991]
	Use as a meta-theory	Walsham and Sahay [Walsham and Sahay, 1996] Kling and Iacona
Analysis	Using specific concepts from Structuration Theory: * Resistance to IS * Changes in work roles * IS strategy * 'Informating' aspects of IS	Lyytinen and Ngwenyama [Lyytinen and Ngwenyama, 1992] Han and Walsham [Walsham and Han, 1991]
Operational studies	Valuable in carrying out or for retrospective understanding of empirical situation; * IS in use, linking action with structure * Process of IS evaluation * System specification * IS design and development	Barley (1986) - CT scanners Walsham and Sahay [Walsham and Sahay, 1996] Orlikowski and Robey [Orlikowski and Robey, 1991]
	Developing practical guidelines on use	Rose [Rose, 1999] Checkland (1991) Walsham [Walsham, 1993]

Table 2.1: Categorisation of application of Structuration Theory to IS research

In this case study, Structuration Theory is used as a meta-theory and as an analytical tool to explain the context (place, culture, infrastructure, political and societal environment, etc.) in which the system is being designed. As a meta-theory, I use Structuration Theory to see how structures can be changed through emancipation and how various accounts of exclusion and vulnerability can be tackled (see Chapter 3)

In addition to using Structuration Theory as an analytical tool, some key concepts, such as time-space distancing, human agency and knowledgeability provide insight into the analysis and design of a CBIS. In terms of the concept of time-space,

the argument is made here that place - part of the context - is very important in terms of developing and designing an IS. It is important to link with the broader network and influence some of the institutionalising factors which affect the context and, therefore, I argue for the linkage with space to make this happen. This leads to a discussion in the final chapters of Castells' network society and an argument for the need to generalise from the case study.

2.3.2 Contemporary application of Critical Social Theory in information system research

Since the early 1980s there have been numerous studies that have explored the theory of Habermas to analyse systems development [Lyytinen and Klein, 1985] [Lyytinen, 1992] [Hirschheim and Klein, 1994]. The application of Critical Social Theory to IS research can be categorised under the following headings, and the literature on this topic is summarised in Table 2.2.

1. *Relationship between theory and practices - criticism of scientism (functionalism):* This category draws on Habermas' knowledge-constitutive interests [Habermas, 1973]. As Lyytinen [Lyytinen, 1992] in his review of literature in this area notes, most of the literature from a 'practical interest' stance, looked at the need for mutual understanding to understand how IS are used in an organisational context. Emancipation is often not discussed, though Lyytinen and Klein [Lyytinen and Klein, 1985] argue that concepts of autonomy and responsibility should also be taken seriously into account in IS research. IS should serve the values of the widest possible audience and should foster criticism and reflection. Most of the research in this area discusses issues around ontology, epistemology and the ethical dimensions of IS research and is useful in raising researchers' awareness around such issues.
2. *Nature of social action and type of knowledge - classification of existing research:* Most researchers in this area look at the four types of social action, in some form, to understand the nature of IS design, implementation and use. Often this entails the criticism that IS research is too focused in the instrumental domain. This approach is useful for organising and evaluating research. Two such frameworks are proposed by Hirschheim and Klein [Hirschheim and Klein, 1989] and Hirschheim, Klein and Lyytinen [Hirschheim et al., 1996]. In

the former [Hirschheim and Klein, 1989], the authors generate four 'paradigms' of IS development using a subjectivist-objectivist axis and an order-conflict axis. Critical Theory would be categorised under the subjectivist/conflict quadrant and is termed 'neo-humanism'. In the latter, Hirschheim, Klein and Lyytinen [Hirschheim et al., 1996] propose a framework for structuring and understanding IS development based on the social action theories of Habermas and Etzioni. Based on this framework, they analyse core IS design research and identify future research domains.

3. *Informing alternative methodological approaches to IS research:* Walsham notes that Lyytinen and Klein [Lyytinen and Klein, 1985] maintained that the Critical Theory can be used "as a basis for a theory of information systems" which strives for the emancipation of people and as such address the constraining structures to this emancipation. Though Walsham notes that this is a commendable goal, it isn't very clear how Lyytinen and Klein propose to do it.

The authors express a wish for methodologies which are more socially open, but when they argue that methodologies should 'enforce authentic communication', they are implicitly recognising the existing structures of power and domination which necessarily constrain the openness of the debate. [Walsham, 1993, p. 12]

In terms of the first application of Critical Social Theory in IS research, I adopt as mentioned in the section on process (see Chapter 4, Section 4.3), a critical interpretive longitudinal approach which is more in-keeping with the ideas and principles espoused by Critical Social Theorists.

In terms of the second application, I use Habermas' theory of communicative action and explore the scope and process of participation by using the idea of the 'Ideal Speech Situation'. In this discussion I focus attention on participation and communication. This is in line with the issue raised in an earlier paper by Lyytinen and Klein [Lyytinen and Klein, 1985] where they argue that

... practical knowledge interest requires participation because, without a great deal of open discussion, an information system development group cannot understand the norms, values and actions of its members.

Application	Basic concepts	Examples:
<i>Criticism of scientism (functionalism)</i>	<p>issues around ontology, epistemology and the ethical dimensions of IS</p> <p>striving for emancipation</p> <p>foster criticism and reflection</p>	<p>Orlikowski and Baroudi [Orlikowski and Baroudi, 1991]- review of literature largely expressed a positivist, short term philosophical root.</p> <p>Lyytinen and Klein [Lyytinen and Klein, 1985] IS research dominated by scientism and adherence to scientific method.</p> <p>Ngwenyama and Lee [Ngwenyama and Lee, 1997] communication richness in computer mediated communication as social act.</p>
<i>Classification - social action and knowledge</i>	<p>four types of social action</p> <p>IS research is too focused in the instrumental domain</p> <p>useful for organising and evaluating research</p>	<p>Hirschheim and Klein [Hirschheim and Klein, 1989] four 'paradigms' of IS development using a subjectivist-objectivist axis and an order-conflict axis.</p> <p>Critical Theory in subjectivist/conflict quadrant.</p> <p>Hirschheim, Klein and Lyytinen [Hirschheim et al., 1996] framework for structuring and understanding IS development.</p> <p>Analyse core IS research.</p>
<i>Methodological approaches</i>	<p>socially open methodologies</p> <p>authentic communication</p> <p>recognition of power and domination as potentially constraining debate</p>	<p>Ngwenyama [Ngwenyama, 1991] methodology for practice oriented research - five requirements of Critical Social Theory</p> <p>Hirschheim and Klein [Hirschheim and Klein, 1994] extend ETHICS* by incorporating emancipatory principles.</p> <p>(*Effective Technical and Human Implementation of Computer Systems)</p>

Table 2.2: Categorisation of application of Critical Social Theory to IS research

... Participation enables the users of an information system to take responsibility for their own language and action and their own definition of organisational reality. Only they can understand their own work situation. [Lyytinen and Klein, 1985, p. 228]

Lyytinen and Klein note that emancipatory knowledge requires participation “... because the rationality of the goals and values of information systems development requires an open and informed debate (a discourse) between equals.” [Lyytinen and Klein, 1985, p. 228] This approach informs the discussion in Chapter 8 on the need to rethink participation in IS design and development.

I use Habermas’ theory of communicative action and the notion of ‘the Ideal Speech Situation’ to explore how developing a public sphere for the discussion of child-health issues can be an effective mechanism in changing the situation of children in UThukela District. Important to the process of striving for transformation was the role of communication and the translation of meaning and concepts. This is in-keeping with the argument of Habermas that communication involves much more than the language used between actors, and incorporates a complex network of social relationships. IS is a social system that can facilitate communication if designed and developed as a developmental tool. This requires the creation of a co-determined vision, the sharing of local meanings and concepts, and the development of localised indicators.

In terms of the third application, I adopt a participatory action research framework in which changes are sought to be made, evaluated, revised and implemented within an iterative process (see Chapter 4, Section 4.3.2). The reasons for adopting the participatory action research approach are outlined in Chapter 4 as well as how the research was conducted, including how data was collected and analysed. As the researcher also comes with his or her own baggage, I reflect, in the same chapter, on my own role as researcher and also as change agent.

In this way, I address the two research challenges outlined by Lyytinen [Lyytinen, 1992, p. 171]:

- development, refinement and criticism of Habermas theory of communicative rationality, and;
- development of methodology that consolidates insights from Critical Theory into organisational action.

2.4 Conclusion

In summary, the theoretical perspective adopted is mainly influenced by two theories - Structuration Theory and Critical Social Theory. Table 2.3 summarises the way

in which aspects and concepts from both of these theories are used.

Example from research	Theoretical concept used
<i>Understanding the context</i> Restructuring of the health system Social traditions and community infrastructure	Structuration Theory (Giddens)
<i>Process</i> Methodology chosen Translation and communication key in IS design Rethinking participation in IS design Modes of analysis	Changing context to improve the human condition (Critical Social Theory) Structuration takes place over time - recursive (Giddens) Structuration is discursive (Giddens) Creation of public sphere (Habermas) Creation of public sphere (Habermas) Understanding context (Giddens) Decision to change situation in hands of community (Giddens and Habermas)
<i>Output</i> Standardisation and localisation Generalisations Changing information flows and communication loops	Connecting with broader structures and connecting to the 'Net' (Castells) Time-space distanciation (Giddens) Creation of public sphere (Habermas). Structuration process at different levels (Giddens)

Table 2.3: Summary of theoretical concepts used in this case study

Concepts from Structuration Theory and Critical Social Theory are used in helping to understand the context by using Structuration Theory as an analytical tool and Critical Social Theory to explain the emancipatory nature of changing those constraining structures. The methodology chosen, the importance of communication and participation, and the analysis of the data collected, are all based on the principles of Critical Social Theory - interpretive, longitudinal, participatory, action research, creation of public sphere and communicative channels to support open and free discussions. The output of the IS design process looks at structuration from a number of different and interconnected levels and examines how generalisations

from one localised setting can be made.

Chapter 3

Vulnerability and Information System design

In this chapter, I explore the contemporary meanings of and debates regarding vulnerability and conclude that vulnerability is not a given state, but a relative contextual concept. Since children move in and out of relative degrees of vulnerability, IS need to be designed that facilitate the monitoring of this changing context. Given that the existing DHIS is facility-focused, children, not accessing the health services, are excluded from that system. Furthermore, due to the differing perspectives and meanings of vulnerability locally-specific indicators, information flows and communication loops need to be integrated into the formal HIS. IS designed in this manner allow communities to air their views and opinions and to paint an accurate picture of all the children in the district¹.

¹The content of this chapter formed the basis of the following paper: E. Byrne. Addressing the vulnerability of children through information systems: A South African case study, proceedings of SAICSIT (South African Institute of Computer Scientists and Information Technologists) conference, 4 - 6 October 2004, Stellenbosch, South Africa

3.1 Introduction

The objective of this research is to improve the care of vulnerable children through the design and development of a child-health CBIS that enables communities to advocate and influence decisions and policies and demand for the realisation of the rights of their children. The fundamental argument of my research is that IS design can be used as a developmental tool and to assist with the care of vulnerable children through its role in advocating for the realisation of the rights of the child. Here I build on Sen's argument of the importance of the informational base in development and decision-making, and focus on capabilities and freedom as aspects of emancipation. After reviewing the existing HIS in South Africa, I conclude that information generated is not being used, but even if it was being used it does not adequately address children. The existing DHIS does not include data on the most vulnerable, which are children who do not access the health services. My conclusion, therefore, is that IS design can be used as a tool to address vulnerability if a child-health CBIS is effectively designed, addresses local understandings of vulnerability and develops capacity to reflect, use and learn from the data generated. In this way the process of IS design can be used as a tool for development and freedom.

In this chapter, I explore the contemporary debate over the meaning of vulnerability. I conclude that vulnerability is not a given state, but is a relative context which changes as time and concept do. Therefore, the key to understanding and addressing vulnerability, is an understanding of the processes which cause vulnerability and including indicators of that process within the IS.

3.2 Addressing vulnerability through IS design

Many vulnerable children rarely have access to health and social services. Health-seeking and care-giving practices are generally poor. Without parents or care-givers, access to health facilities is often denied. Knowledge of their rights and entitlements is often limited and that exacerbates their inaccessibility of health services. Often, children do not have the necessary documentation to access the services, such as the need to have a birth certificate to apply for the government child-support grant. Children live in communities and communities have knowledge of their children. By developing and designing a child-health CBIS, children can be included in the DHIS and the situation of their vulnerability may then be highlighted.

Sen [Sen, 1999, p. 44] states the case for a strong relationship between public expenditure on health-care and poverty, and argues strongly for an informational basis of this connection. Information on health can be used to explain, more generally, the developmental context of a society. Improved information infrastructure in these marginalised communities, can lead to better health services because of increased transparency and increased opportunity for political and social pressure. Through a parable (Annapurna wanting somebody to dig her garden, but finding it difficult to choose one of three labourers, as each would be chosen if different criteria, such as poverty, unhappiness and illness, was used to inform the making of the decision) Sen explains how decisions made are dependent on the informational base and indicators selected [Sen, 1999, p. 54]. So the process of IS development clearly determines the picture created and views expressed. Equally important to the information that is included is the information that is excluded.

Using a different example from Chapter 1, Section 1.1.1, I reiterate the point, that the HIS inherited by the Government of South Africa, reflected the political nature and social structures of that government.

In creating independent bantustans, the government has stripped at least eight million South Africans of citizenship. These people, living in some of the unhealthiest conditions in the country, have disappeared from official health statistics. For example, the number of officially reported cases of TB dropped between the mid 1970s and the early 1980s in South Africa. From the end of 1976, TB cases in the Transkei stopped appearing on the South African statistics. As the area has probably the highest incidence of TB in the country, this event would by itself have led to a major reduction in the number of notifications. Official state policy not only helps to cause ill health and limit availability of health care, it also refuses to document the deaths which occur. [de Beer, 1986, p. 76/77]

There are a number of examples where IS have been used to address vulnerability, often with NGO's acting as intermediaries. NGO's are useful in terms of their place in the global flows of information as well as being present in a local context. They have the ability to influence both agendas and also access various media, such as ICT, for communication [Madon, 2000].

Madon [Madon, 2000, p. 13] gives the example of an NGO, Jana Sahayog, based

in Bangalore, whose aim is to improve the information environment of slum dwellers in the city. Recognising that much critical information comes in through informal sources from slum dwellers themselves, Jana Sahayog tries to identify and enhance traditional communication skills in the slums. For example, slum dwellers are encouraged to produce audio cassettes and videotapes describing their problems and requirements.

Madon and Sahay [Madon and Sahay, 2002, p. 15] give another example of a community-based organisation (CBO), Mazdoor Kisaan Shakti Sangathan (MKSS), who used the right to information to combat corruption in famine relief works in India. Through their successful work, they were able to successfully demand a law that would guarantee the right to information for every citizen. The long term impact, in terms of accountability of public servants to its citizens, was minimal. “The MKSS case shows that, in addition to information on government policies, citizens also need knowledge on how to interpret that information to hold public servants accountable.” [Madon and Sahay, 2002, p. 15]

Heeks describes a case in the township of Alexandra, in Johannesburg, in South Africa, to create a database of local resources. All organisations were asked to provide details of their organisation through a process often organised by school children as homework. The database was made accessible over the Internet and provided information about local resources. Through this database, some of the organisations won contracts with larger companies in Johannesburg [Heeks, 1999, p. 13].

NGO’s can network in global alliances, such as CORE, a collaborative organisation of 26 international non-profit-organisations, concerned with child health. However, most of the influence of national, and even international, NGO’s has been on the local level [Madon, 2000]. Even with local case successes, the flow of information is often exogenous rather than the dissemination of indigenous knowledge amongst communities and to policy and decision-makers at higher levels. For intermediaries to have influence there is the need to develop “information sharing and learning culture capacities” [Madon, 2000, p. 13].

The importance of communication aspects of ICT’s is also raised by Heeks [Heeks, 1999] “Information and communication technologies may, therefore, have a greater role to play in giving ‘voice’ to the poor; that is, in making the poor information providers more than information recipients.” Most ICT’s and IS design do

not enable marginalised people to demand information that is useful to them nor enable them to disseminate their own information. There is still the need to connect to the informational society, and accessing technology can improve that connection. The connection, however, needs to be determined in community terms and within their resources (human, financial and time). Accessing ICT carried information requires a lot of resources and the poor simply do not have them. The main strategy, therefore, has been to provide ICT's to intermediaries such as government agencies, NGO's and CBO's [Heeks, 1999, p. 7]. Though Heeks in the next quote is referring to small-scale enterprises in developing countries his comments are relevant to the adoption of ICT's in many other contexts:

ICT's are neither a universally necessary nor a sufficient condition for giving voice to poor entrepreneurs. In the first case, there are many other - potentially more appropriate - mechanisms to assist the poor, from face-to-face meetings to telephone conversations to newsletters and even radio/TV programmes. On the second point, technology only affects part of a much broader social process. Poor entrepreneurs must also have the capacity to generate relevant information about themselves, and to access and use the ICT's. Frequently, they do not have this capacity, and they will again have to rely on intermediaries. At the other end of the transmission chain, someone must also be listening and able to act on what they hear. [Heeks, 1999, p. 12]

Technical constraints of information technology should not be the main determinant of what type of IS can be implemented. "Technology per se doesn't solve problems. But the availability and use of information and communication technologies are a pre-requisite for economic and social development in our world" [Castells, 2000a, p. 3]. The development of learning and reflexive capabilities with an emphasis on communication loops and information flows is addressed in this research.

3.3 Meaning of vulnerability

Vulnerability is a highly relative concept and is, therefore, context specific. As Beck, Madon and Sahay note, "conditions of exclusion and marginalisation should not be treated as an 'either-or' state of being" [Beck et al., forthcoming 2004]. In the impoverished areas of South Africa, vulnerability has a different meaning, not just

compared to other more affluent areas, but also among the different community members themselves. What became apparent from my research was that often people who were viewed as vulnerable by others within the community, did not view themselves as vulnerable - the informational basis used by the participants on drawing that conclusion differed. With the continuous change in this context, views of vulnerability also change.

This is a view endorsed by the findings of Giese, Meintjes, Croke and Chamberlain, [Giese et al., 2003] when they explored the health and social services capacity to address the needs of orphans and other vulnerable children in the context of HIV/AIDS in South Africa. Though in relation to defining orphanhood, their concerns in trying to develop a common definition that would hold meaning for all, is also applicable to vulnerability. They argue that international definitions of orphanhood do not

...encapsulate important aspects of vulnerability that children commonly face before the death of their parent(s) or care-giver(s), in particular from HIV/AIDS and other terminal illnesses. Nor does it recognise the multiple child-raising and caregiving forms operative in South Africa, and the fact that children can be rendered similarly vulnerable by the illness or death of adult caregivers who are not their biological parents. Furthermore, it does not take account of the prevalent local definitions of orphanhood and vulnerability which do not necessarily identify as orphans children who have lost biological parents if they are in the safe and consistent care of other relatives, and which are in many instances associated with a set of negative connotations. [Giese et al., 2003, p. 24]

This raises the question of who defines vulnerability. There are a number of common definitions of vulnerability which I explore here. Some are based on abstract conceptual debates, whereas others are based on practical experience. The first definition falls within this latter category.

3.3.1 Vulnerability and HIV/AIDS

Vulnerability, in the context of this research, is exacerbated by the HIV/AIDS pandemic. “Although the majority of South African children share the burden of acute resource constraints ... researchers argue that children living in households directly

affected by HIV/AIDS are among the most vulnerable to rapid socio-economic decline.” [Giese et al., 2003, p. 50] However, HIV/AIDS is not the sole cause of vulnerability.

Though we need to understand the causes of vulnerability, trying to divide vulnerability into different categories based on different causes does not address the fact that most of the causes of vulnerability overlap and co-exist. We cannot tackle only one aspect and succeed. Giese, Meintjes, Croke and Chamberlain [Giese et al., 2003], note that most of their research participants located vulnerability firmly within a broader context of poverty and difficulty, arguing that children living in poverty-stricken, HIV/AIDS-affected communities are all vulnerable. They argue that:

There are few vulnerabilities in children’s lives that can be attributed solely to the onset of ‘orphanhood’. The experiences of children who participated in this research have been repeatedly demonstrated through the course of this chapter to overlap not only with many of those documented for children living in poverty . . . but also with children affected by HIV/AIDS in other ways . . . , in some instances with children living with caregivers suffering from terminal illness other than AIDS, or with children who had lost a parent or caregiver to other causes, as well as with children who live alone, with the elderly, with relatives or with others for reasons other than orphanhood. [Giese et al., 2003, p. 72]

They conclude that:

On the basis of an examination of national household survey data collected from 28 countries across the world (most in Sub-Saharan Africa), Ainsworth and Filmer (2002) argue that the assumption that orphans are more vulnerable than other children is incorrect since the situation for children varies from country to country depending on, among other things, the local economic and political context. They document diversity in school enrolment figures for example which are not - as is often assumed - always lower for orphans than for children who have living biological parents. [Giese et al., 2003, p. 162]

3.3.2 Social exclusion and marginality

Beck, Madon and Sahay analyse, on a more theoretical level, the meaning of social exclusion when exploring the role of mediation in addressing exclusion in two different urban settings [Beck et al., forthcoming 2004]. According to the original French usage of the term, social exclusion was defined as a 'rupture of the social fabric' attributed to a failure of the state and the focus was on relations between the state and citizens. The term exclusion has been used more broadly since the 1980s and is often used to identify various types of social disadvantage in employment, education, housing, health, and social networks. The term used is along similar lines in developing countries with the focus on assessing the problems of systematic and multiple deprivations including the various psychosocial factors involved. So social exclusion is a complex and multifaceted condition and focuses attention on what Sen calls the 'relational roots of deprivation' [Sen, 1999]. Beck, Madon and Sahay note that an important gap in the literature on social exclusion has been an explanation of how the conditions of social exclusion are created, sustained and redefined over time [Beck et al., forthcoming 2004].

Beck, Madon and Sahay [Beck et al., forthcoming 2004], further explore the concept of the related notion of marginality. One key writer they quote is Gino Germani. For Germani, marginality depended on historical and cultural expectations from self and others. Germani emphasised how these conditions are reproduced and become structural. Beck, Madon and Sahay explore the extension of Germani's concept of marginality by Svedberg (1995), who describes four main views of marginality: as cultural split, as a (personal) social-psychological dilemma, as socio-cultural isolation, and as partial socio-economic participation [Beck et al., forthcoming 2004, p. 9]. Marginality is, therefore, a position on a continuum, the end points being 'anchored' and 'outcast'. Being marginal is considered to be a volatile position which implies the possibility at any point in time of moving closer to one of the extremes along a continuum [Beck et al., forthcoming 2004]. The focus in Svedberg's context is on economic participation at the individual level.

3.3.3 Globalisation and exclusion

Contemporary times have seen an increasing debate on the role of marginalisation and globalisation. Globalisation is accompanied by rising inequality [Madon and

Sahay, 2002, p. 1]. The work of Castells [Castells, 2000a] explains how the structures in place in a global economy reinforce the exclusion of vulnerable people and how important it is to tackle this exclusion by ensuring that they are linked to the rest of the global market. Castells refers to the groups of people affected by this inequality as the 'Fourth World'. These people and regions in the world are excluded from the economic flows associated with globalisation. The 'Fourth World' is consists of multiple black holes of social exclusion [Castells, 2000a].

Thus, the new, global economic system is at the same time highly dynamic, highly exclusionary, and highly unstable in its boundaries. While dominant segments of all national economies are linked into the global web, segments of countries, regions, economic sectors, and local societies are disconnected from the processes of accumulation and consumption that characterise the informational/global economy. [Castells, 2000a, p. 102]

Globalisation is selective and conditions of history and geography shape the access that groups and societies have to global flows.

Castells, along with other authors, would argue that a key factor in being included in the information society is the connection of individuals and society to networks of information [Castells, 2000a] [Madon and Sahay, 2002].

ICT's (information and communication technologies) are not inherently a cause of exclusion, but lack of access to the means of communication increasingly used by the rest of society has the potential to systematically worsen the relative position of excluded individuals and groups. . . . While writers have emphasised the need to build "informational networks" to combat marginalisation, less has been written about how this can be done in practice and the underlying challenges that exist. [Madon, 2000]

As a result large segments of the population are cut off from the new technological economic system.

An important concept in this system is the 'network'.

A network is a set of interconnected nodes and has no centre. They are old forms of social organisation but within the new technological

paradigm have increased their flexibility and adaptability. . . . An information network that executes instructions from the dominant values and interests in a society constitutes the Net. [Castells, 2000a, p. 41]

Within the network, individuals are searching for their own identity. Finding meaning for oneself becomes an increasingly difficult and ever-changing task and is a source of anxiety. Increased feelings of alienation and social fragmentation accompany the process of increased exclusion [Castells, 2000b] [Giddens, 1991b]. So, although globalisation can impact on exclusion at a global level, it can also generate causes of vulnerability on an individual level.

3.4 Meaning of vulnerability in this research

As Robert Chambers notes in his book on *Whose reality counts? Putting the last first* [Chambers, 1999], local people's assessments of their situation are more knowledgeable and nuanced than assessments by outsiders. In looking at well-being, he illustrates that well-being is a local, complex, diverse and dynamic reality. Well-being is multi-dimensional. Rarely can well-being be explained in terms of one factor. The quote from Delia Paul illustrates this point:

One of the things we found in the village which surprised us was people's idea of well-being and how that related to having money. We talked to a family, asking them to rank everybody in the village from the richest to the poorest and asking them why they would rank somebody as being well off, somebody as being less well off, and someone as poor. And we found that in that analysis money meant very little to the people. The person who was ranked as poorest in the village was a man who was probably the only person receiving a salary. But that did not count to the villagers because he did not have cattle, he was not married, and he did not have any children. So the money on its own did not sort of mean anything. What was important was that they could have a certain lifestyle, that they were able to entertain with generosity, and that there were many children around them. [Chambers, 1999, p. 179]

Though many people would argue that there are few people who would suggest that vulnerability can be measured by income alone, major national and global decisions

in the developmental arena are still based on per capita Gross Domestic Product (GDP) or Gross National Product (GNP). The basis of the argument that access to a social grant will alleviate poverty rests on the implicit assumption that poverty can be measured and addressed by income.

The view that poverty is simply a shortage of income is fairly well established in the literature on the subject. It is not a silly view, since income - properly defined - has an enormous influence on what we can or cannot do. The inadequacy of income is often the major cause of deprivations that we standardly associate with poverty, including starvation and famine. In studying poverty, there is an excellent argument for beginning with whatever information we have on the distribution of incomes, particularly low real incomes. [Sen, 1999, p. 72]

So, in terms of defining vulnerability we cannot accept one definition that is applicable to all. What is needed is the development of a definition that is context specific and moves beyond a simple measure of income. This means that we must ask and listen to what people view as important in relation to well-being and vulnerability. Thus, part of the fieldwork for this research explored and gathered the views of people on how they perceived vulnerability and well-being. Freedom from vulnerability also implies capacity and freedom to participate in the decisions and events that directly affect one's life. This is close to Sen's view of 'development as freedom'.

What people can positively achieve is influenced by economic opportunities, political liberties, social powers, and the enabling conditions of good health, basic education, and the encouragement and cultivation of initiatives. The institutional arrangements for these opportunities are also influenced by the exercise of people's freedoms, through the liberty to participate in social choice and in the making of public decisions that impel the progress of these opportunities. [Sen, 1999, p. 4]

Therefore, it is also important to go beyond an understanding of vulnerability in a local context, to exploring how vulnerability can be addressed and what capacity is needed in order to change the context which shapes the vulnerability.

In summary, IS design and development can be used to address exclusion and vulnerability. As seen from the examples given above, vulnerability has been ad-

dressed using IS. Some of the failures in using ICTs to address vulnerability, even with using NGOs as intermediaries are: focus on accessing information from outside rather than disseminating their own information; not developing capacity to access and demand information that is useful to them, and establishing technological communication networks which are culturally and traditionally inappropriate nor have been demanded by the users of the system. The IS designed in OKhahlamba Municipality attempted to address these failings. The IS was based on culturally appropriate communication channels. As a result communication and information flows rely primarily on face-to-face communication at the local level. The data collected is used to calculate community determined indicators. It is from this data that certain indicators are calculated and sent to the district. Through the Department of Health and the Project the CBIS is connected, through the computerised DHIS, with the broader social processes at national and global levels. Capacities to reflect and learn from the data collected were also emphasised, so that people could air their own views through the IS.

For the purposes of this research, vulnerability is a relative concept and needs to be locally defined. It is multi-dimensional and measures of HIV prevalence or income alone are insufficient in defining it. Globalisation can reinforce the vulnerability and impact these local structures and conditions. The key assumptions about exclusion, based on those developed by Beck, Madon and Sahay [Beck et al., forthcoming 2004], in this research are:

- Social exclusion is relative in nature, and thus processual.
- Exclusion is contingent upon social relations and institutions of society and is not measured in a single dimension.
- Those marginalised have a potential to act and this capacity needs to be developed.
- Mediating institutions can play a potential role in leveraging action.
- Rather than being fully included or excluded, marginalised groups may occupy a position in-between with the potential of movement between these positions.
- Vulnerability needs to be addressed through access to information and communication flows (a participatory approach to CBIS design can assist in this respect).

To illustrate that appropriate CBIS for forming a comprehensive DHIS are virtually non-existent, the next section describes the existing HIS in South Africa.

Much has been done in the area of HIS since 1994. The absence of CBIS and the lack of data generated from existing IS's that is relied upon for decision-making are still major causes of concern. It is at community level that the information needs to be made available regarding children's vulnerability and where immediate action needs to be taken.

3.5 The development of the District Health Information System

This section explores the developments of the DHIS since 1994. To place these developments in context, I first provide a brief overview of the national policy and priorities of the Government of South Africa and the National Department of Health that impacted on the development of the HIS at national, provincial and district level.

3.5.1 The National Health Information System

With the national elections in 1994, the South African Government embarked on a process of health system transformation which involved:

- focusing on preventive PHC, rather than predominantly curative care;
- making health services more accountable to the communities they serve, through the establishment of a DHS, and;
- unifying the previously fragmented services. [Braa and Hedberg, 2002]

The first phase of this transformation was the introduction, on 1 June 1994, of free health-care for pregnant women and children under the age of six years. The second phase was the introduction, on 1 April 1996, of free PHC services for all clients. The government's objective of achieving universal access to PHC, and prioritisation of vulnerable groups such as the poor, women and children, is viewed as progressive, poor-friendly and sensible, though services for the poor, especially the rural poor, are still inadequate.

In the White Paper on Health, the government acknowledged that:

The lack of reliable health information is one of the major obstacles to the effective planning of health services in South Africa. The health

sector has, therefore, given priority to the development of a new national HIS and aims to contribute to the promotion of an information culture in South Africa. [Department of Health, 1997, Chapter 6, p. x].

In addressing this priority, one of the first steps in this direction was the establishment of a Committee by the Minister of Health in 1995. The Committee consisted, and still consists, of the Provincial Members of the Executive Committees for Health (similar to Provincial Ministers) and representatives from the National Department of Health, other relevant government departments, academic and research institutions, and the private sector. The membership of the IS committee is currently (2004) being reviewed.

The principles as set out in the White Paper for the development of a comprehensive NHISSA were:

The National Health Information System ...should be nationally co-ordinated in order to support the effective delivery of services at all levels of the health system. The NHISSA should be used to monitor the implementation and success of the health priority programmes, both of the Department of Health and the RDP. Reporting of NHISSA data at all levels should be timely, accurate and complete. [Department of Health, 1997, Chapter 6]

The policy and strategy adopted for the NHISSA development were broadly based on five pillars [Mandil, 1995, p. 1/2]:

- IS development was to be based on the health policies and strategies adopted for the RDP.
- It was to be based on a consensus between the provincial and national institutions that would be the primary users of the resulting system.
- The National HIS would be viewed and developed as one parent system, with a number of component systems, governed by nationally-accepted standards on the methodology, technology and procedures used for the NHISSA development and operation.
- The guiding principles for the HIS data and information is that data is to be collected at the point of its generation; data collection is to enable service assessment as well as self-assessment, service delivery personnel would have the responsibility for the collection of data relevant to their specific duties.

- Resources for the ongoing operation and further development of the HIS would, ultimately, have to come from a re-orientation of resources of the respective health authorities at provincial and national level.

The objectives for the HIS included ensuring the availability of information on cost, efficiency, volume and coverage; measuring the health status of the people of South Africa; monitoring the RDP priorities, as well as measuring the progress of implementation of RDP priorities. The RDP also explicitly emphasises the importance of having a National HIS:

An effective National Health Information System is essential for rational planning and must be introduced. This system must ensure that accurate and comparable data are collected from all parts of the health system, that data are analysed at the health facility, district, provincial and national levels, and those collecting the data see it as a useful and interesting activity. Mechanisms must be established for sharing information between different programmes and sectors. [African National Congress , ANC, p. 49/50, para 2.12.9.7]

Community participation and 'children first' are clearly specified in the RDP, the South African constitution and local government legislation. With respect to HIS the priorities of community participation and 'children first', are only clearly mentioned when the strategies to be adopted in setting up the HIS are outlined. The priorities are not explicitly part of the goals or pillars of the HIS. Implicitly though, these priorities are given attention in the documentation on the development of the NHISSA in two ways:

- Under the need for cause-specific mortality and morbidity data, especially for children and women, it is stated that this data would *serve as indicators of development*².
- The importance of information flows which include the community is illustrated in the following section of the White Paper:

Emphasis will be placed on the use and feedback of data at all levels, especially at the point of collection. Regular NHISSA bulletins will be produced at the national level. It is envisaged that mechanisms for data dissemination will be established at the provincial

²own emphasis

and district levels. It is essential that data be made available to decision-makers, planners and communities, and that it is used to influence resource allocation and reduce inequity. [Department of Health, 1997, Chapter 6]

Provincial and district level working groups were to be established to facilitate the development and implementation of these systems on an incremental basis. In addition, community level surveillance would be developed and implemented with the communities' active participation. District Health Management Teams were tasked with assisting the communities to develop the capacity to assess their own problems and identify appropriate remedial actions.

In line with the principle of building on existing structures where possible, the committee carried out some research on the existing HIS. The main findings of the review of these systems [Mandil, 1995, p. 6] were that they:

- are fragmented and incompatible;
- incorporate inadequate analysis and interpretation of data at local levels;
- are mainly used for budgeting and personnel purposes;
- need to be restructured and standardised if useful information is to be collated from them;
- do not provide for other data required, such as population-based estimates and other analysis;
- have mostly manually-driven facilities with minimal computerisation, and;
- where computer-supported, the software and hardware are incompatible with other systems, and are not particularly user-friendly.

Once the conceptual model for the NHISSA had been agreed upon and the linkages between national and provincial levels established the NHISSA committee also agreed to have a minimum data set and standards in place:

The Committee agreed that minimum standards for methodology, implementation, data, codes, coding schemes, applications software, a data base management system, networking and communications protocols and other important standards, are essential and needed the NHISSA development and operation. [Mandil, 1995, p. 6]

It was further added that though there was the need to be in line with international indicators, provinces' information needs sometimes differ. Provinces should decide

on additional specific indicators related to their needs.

The minimum national dataset for PHC at a district level as of November 2002 (see Table 3.1) has an increasing number of data items relating to child health (under 5 years). From this data set, the national indicators for child health are calculated and are given in Table 3.2. In the second column, the revised minimum data set is also given (approved by the NHISSA committee, in principle, on 16th August 2002 but still awaiting approval from Provincial Health Restructuring Committee (PHRC)).

Data items
PHC headcount under 5 years
Diarrhoea under 5 years - new
Lower respiratory infection under 5 years - new
Child under 5 years
Not gaining weight under 5 years
Severe malnutrition under 5 years - new
BCG at birth
DTP-Hib 1st dose
DTP-Hib 3rd dose
OPV 1st dose
OPV 3rd dose
HepB 1st dose
HepB 3rd dose
Measles - 1st dose at 9 months
Immunised fully under 1 year - new
Measles 2nd dose at 18 months
First antenatal visit before 20 weeks
Live birth under 2500g

Table 3.1: National data items for child (under 5 years) health, 2002

There are problems in the working relationship between child-health programmes and health information units at different levels within the Department of Health. The data flow policy, which has recently been approved by NHISSA committee, sets the framework on how the above-mentioned relationship should work. Hopefully, since the data flow policy has been approved, this situation will improve. Advocacy and communication at all levels is needed to improve this relationship.

Indicator	As of Nov 2002	As in revised data set
Antenatal visits per antenatal client	X	
Antenatal visits before 13 weeks		X
Antenatal coverage		X
Antenatal visits per antenatal client		X
Low birth weight	X	X
Immunisation coverage under 1 year (monthly)	X	
Immunisation coverage under 1 year (annualised)	X	X
Immunisation drop-out rate (DPT-Hib3-Measles 1)		X
Immunisation drop-out rate (DPT-Hib1-Hib3)		X
OPV 1st dose coverage		X
OPV 3rd dose coverage		X
Hep B 3rd dose coverage		X
Measles coverage under 1 year (annualised)	X	
Measles 2nd dose coverage (annualised)		X
BCG coverage	X	
Vit A coverage under 1 (annualised)		X
DT at 5 years coverage		X
Children under 5 weighed		X
Not gaining weight under 5 years rate	X	X
Underweight for age		X
Incidence of severe malnutrition under 5		X
Diarrhoea incidence under 5 years		X
Diarrhoea incidence under 5 with dehydration		X
Diarrhoea incidence under 5 with no dehydration		X
Pneumonia incidence under 5		X
HIV positive rate under 5 years		X
<i>Optional</i>		
Vitamin A coverage 12-60 months (annualised)		X
Symptomatic HIV infection rate under 5 years		X

Table 3.2: National indicators for child health (existing and revised)

3.5.2 Provincial Health Information Systems

The provinces' representatives form the majority of the NHISSA committee membership and thus play a major role in the development of the NHISSA system and its components. With the setting up of NHISSA, the committee members agreed to the terms of reference for the committee and the conceptual view of the overall

NHISSA was agreed upon.

...that the NHISSA be viewed as the overall parent national health information system of South Africa, comprising of various component systems (or sub-systems), individually and collectively providing the various types and formats of information (managerial, statistical, epidemiological) on and for the Health Care Services of South Africa. [Department of Health, 1997, Chapter 6]

At the provincial level, committees were established to facilitate the implementation of a streamlined HIS, based on the national guidelines. The provinces are also responsible for facilitating the development of a DHIS.

All the component parts of the NHISSA do not need to be implemented in full by all provinces. The provinces decide on the component systems which best suit their own needs. However, they should adhere to the prerequisites of national priorities, cost effectiveness and compatibility, and fully respect the standards set by NHISSA committee for such purposes. The provinces were also tasked with ensuring that there is no duplication of data collection. “.. the national department should play a mediation role to assist in ensuring access to information by those who need it and are authorised to access.” [Mandil, 1995, p. 5]

3.5.3 The District Health Information System

A Task Team comprising officials from the District Health Systems, the National Health Information System Directorates and other professionals, developed District Health Information Guidelines. These were published in February 1998 [Health Systems Trust and Department of Health, 1998]. The role of the community or local level role proposed DHIS is illustrated in Figure 3.1.

Parallel to this process, some of the members of the Task Team, specifically those from the Health Information Systems Project (HISP), were simultaneously involved in DHIS pilot projects. The HISP began as a collaborative research project between the University of Cape Town, the University of Western Cape, the Norwegian Computing Centre, and the Provincial Administration of the Western Cape. The Norwegian Agency funded the 1st phase of the project from mid-1996 to the end of 1998. Work from these pilot projects resulted in the development of a free software system designed for the collection and management of data at district

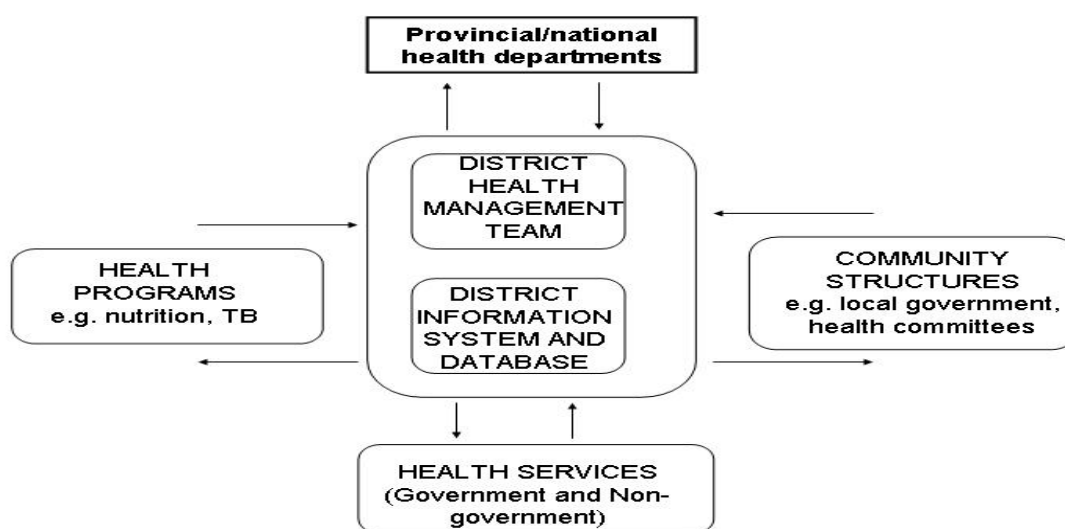


Figure 3.1: Proposed District Information Model with all components

level - the DHIS software. In its first pilot phase (1996-1998), the project aimed at developing DHIS to support the emerging decentralised administrative structures in three pilot districts in Cape Town. In February 1999, based on some of the achievements of the pilot phase, the Department of Health in South Africa adopted the strategies, processes, and software developed in the pilot districts as the national standard [Braa and Hedberg, 2002, p. 113]. Currently, all districts use the standardised DHIS software based on HISP.

The objectives of HISP were to roll out an action-led district health management IS which allowed health staff in local clinics to take control of, and benefit from, their own health information. More specifically, the HISP design team hoped for:

- a shift of control of IS from central towards local levels, that is, to more equal control between central and local levels;
- local flexibility and user orientation (it should be easy to adapt the software to local conditions);
- support for health sector reform towards decentralisation and the development of health districts, that is, integrating the vertical flows at district level;
- empowerment of local management, health workers and communities, and;
- horizontal flow of information and knowledge based on the principle of free access to all, anonymous and aggregated health data/information. [Braa and

Hedberg, 2002, p. 122]

These principles mark a radical contrast to the HIS which was already in place in 1994 and which, as mentioned above, was a centralised top-down system designed to support the apartheid structures and policies [Braa, 1999] [Braa and Hedberg, 2002].

Two concepts which were central to the HISP were standardisation and participation [Braa and Hedberg, 2002]. Both these concepts, though using differing approaches, were also used in the development of the CBIS. The necessity of standardisation, whilst being cognisant of contextuality, is explored later in terms of the need for indicators, designed at a local level, to have the same meaning for all. The principles of participation were central to the process of DHIS software design and to my research in developing a CBIS. A participatory prototyping approach was used in the development of the DHIS software, whereas a very different approach (Participatory Action Research - PAR) was used in my research (see Chapter 8).

The HISP is currently ongoing, in different degrees and rhythms, in various countries including Mozambique, India, Tanzania, Ethiopia, Malawi, Mongolia, Cuba, Ethiopia, Nigeria and China [Braa et al., 2004]. HISP seeks to strengthen processes around the design, implementation and sustainability of HIS, with a focus on the local level, and building the capacity of health workers to use information more effectively and operate ICT's for this purpose. In South Africa, HISP continues as a collaborative venture between the University of the Western Cape, the University of Oslo, supported by the Norwegian Government, and various health administrations within the South African Government.

Currently, data is collected at facility level manually, using the daily sheets that are collated monthly and sent to the district office. The District Information Officer receives monthly reports from each health facility. At the district office the data is captured on to a computer and aggregated before being sent to the provincial office. The software package, which supports the DHIS, consists of a set of integrated data collection and reporting applications written in MS Access³. Most of the district and provincial offices have computers.

The province aggregates the district data. Population data is estimated for

³MS Access forms the 'back end' data repository, MS Excel allows the manipulation of indicators using pivot tables, and MS Word and Power Point form the reporting 'front end' [Thompson, 2003, p. 15].

national, provincial and district levels using the 1996 census. The headcount from the facilities is used to calculate an estimate of the catchment population for each health facility. New estimates based on the recent census (2002) are being worked on. The data is transmitted to the National Department of Health in two ways:

- The PHC Form, consisting of the national minimum dataset, is submitted on a monthly basis via e-mail and then imported to the provincial data set in the DHIS Software.
- As the HISP Team is still building capacity at both the national and provincial office, data is also sent to the HISP team, and then to the national Office, on a computer disk.

Though there has been resistance to change and there is still some opposition from other stakeholders within the HIS field, the Department of Health has increased effort, nationally and provincially, to support the development of a DHIS. All districts in South Africa are now implementing a similar DHIS with similarly designed information flows. Research is currently ongoing regarding how effective the use of the information collected is [Williamson and Stoops, 2001] [Williamson et al., 2003] [Braa and Shaw, 2003] [Routine Health Information Network, 2001]. DHIS software for PHC data has been standardised. In conclusion, perhaps the most notable success of the HISP has been the the development of the first-ever unified health information data set on the African continent, establishing the basis for state-wide comparisons of health indicators [Thompson, 2003, p. 15]. The lack of a CBIS that supports the facility IS still means that the goals and objectives, as set out in the RDP and the proposed district information model, have still not been fully met. It is these gaps, the use of information and the development of a CBIS, that are being explored by a joint research project with the University of Oslo and the University of the Western Cape. My research, presented here, forms part of this broader project.

3.6 Conclusion

If the situation that children are currently in is to be changed, people need to be able to demand for the realisation of the rights of the children and to advocate for, and argue that, the commitment of the government to those children is honoured. There is also the need to understand 'vulnerability' from the context in which the

IS is to be designed. As 'vulnerability' is a process and a situation in which children can move into and out of, there is a need to include in IS, a means by which this situation can be monitored. There is also the need to develop the capacity to use the data, generated from IS, so that those demands can be made. To further prevent exclusion from processes occurring at higher levels, there is also the need to connect with those levels. The current district facility IS shows potential in this respect. This leads to the following research questions that I seek to address through my study:

1. What is the vision of the community for the health of their children?
2. How does the existing DHIS assist with the assessment of the situation of children's health and in identifying action to be taken with respect to the vision of the community?
3. How can information flows be designed to facilitate the integration of the CBIS with the formal health facility IS?
4. What changes have occurred, in terms of highlighting the health status of children, in the community and the health systems, since the new IS has been introduced?
5. What role does participation play in the design of a CBIS that supports the realisation of children's right to health?
6. What role does communication play in the design of a CBIS that supports the realisation of children's right to health?
7. What are the theoretical implications of the experiences gained from the case study?
8. How can case experience, from a localised setting, be integrated into broader level structures to effect longer institutionalised change through practical and empirical generalisations?

The next chapter focuses on the design and methodology used in addressing these questions.

Part II

Research approach and context

Chapter 4

Research design and methodology

As the role of the researcher also affects the research process adopted, I commence this chapter with a brief account of the role that I have played throughout the process as well as describing my background in the development of the IS. The chapter continues with how the research was conducted to answer the research questions posed at the end of the last chapter. I then present the reason for adopting, from a Critical Social Theoretical perspective, a participatory action research approach. Given the participatory nature of the investigation, the approach was participatory not just in the collection of the data, but also in the design and implementation of the CBIS. Methods such as PLA, mapping, focus group discussions and interviews were all used. Various modes of analysis were employed, with the data collection and analysis being recursively implicated in one another.

4.1 Introduction

In this chapter I outline the research philosophy, methodology, time frame and analysis which were used in the research approach adopted. I, firstly, outline my own role so that, as a reader, you can better place me in the context of the research. The research team which was established performed the fieldwork in addition to their regular daily functions and provided input into an iterative data analysis process. Given the focus on the social aspects of IS development, in which values, beliefs and the social construction of meaning are central, this research adopted a critical interpretive stance. This stance is consistent with the theoretical focus (Structuration Theory and Critical Social Theory), the empirical research strategy, the action research and interpretive case study, and also with the data collection and analysis process that was adopted. After outlining my role as a researcher, the research approach I adopted, characterised by three key features, is described: interpretive, action research, and longitudinal. Details of the data collection process and the various modes of analysis follow this description. The chapter concludes with the ethical issues addressed in the research process and some of the limitations of the study as interpreted by myself and other members of the research team.

4.2 Role of the researcher

As Lyytinen notes "IS researchers are often refugees from other scientific camps. They have brought their own paradigmatic glasses to the IS research community." [Lyytinen, 1985, p. 66] My background is in the social sciences and in particular with the management of child-health and development projects. This background is reflected in the choice of theories and concepts used. It further informs the underlying argument of this thesis, that IS can be, and should be, used as a tool for human development.

I have been engaged in all of the processes around the TDCSP since 1997, and my involvement continued until the Project ended in 2003. I started at the initial stage of proposal-writing for funding, whilst working at UNICEF. UNICEF supported the development of learning sites for community child-health interventions. After leaving UNICEF, I was approached by the Project managers in 2001 to facilitate the development of the child-health monitoring framework and IS, an aspect of the community child-health intervention that had not been developed at that point in

time. In general, my role at the community level in development of a child-health CBIS, and in support of the Project, has included various activities, such as:

- facilitation of meetings to develop a common understanding of the role of IS in supporting the community's and district's vision for child health;
- training the research team on data collection techniques and instrument design;
- conducting the fieldwork with Project staff and district health staff;
- facilitating group data analysis sessions;
- writing interim progress reports throughout the process and facilitating feedback sessions on the reports with the community and Project staff;
- providing training in the use of revised data collection tools, and;
- acting as the internal evaluator for the DHIS at the mid-term and end-of-project evaluations.

In addition to the local community level, I have also been working with the health structures at the national and district level. I am a member of the National Community Child-Health Committee and present progress reports to this committee at quarterly meetings. This committee comprises national and provincial heads of child health directorates, research organisations, academics, UNICEF, NGO's and CBO's. I further present progress reports at international donor meetings and child-health conferences on behalf of TDCSP. The National Department of Health, with support from UNICEF, requested that I also work in other sites on the design and development of a child-health CBIS, based on these reports and the perceived need for such an IS throughout the country. Guidelines on developing a community-based monitoring system have been written, based on the experience in the UThukela District and in the Limpopo Province. I help provide a link from the community, through the Project, to the national and even international level structures.

When I commenced with TDCSP, I was viewed by Project staff members as the outsider. However, over the years of my involvement with the Project, this perception has changed. For example, in the evaluation of the first phase of the Project in 1999, I was the external assessor to the child-health intervention, whereas, in the final assessment of the second phase of the Project in 2003 I had become the internal assessor of the DHIS intervention. This involvement has given me greater understanding of the Project and the context in general. However, I am sure, in some ways it has also blinded me to certain issues or explanations that a total

newcomer would pick up and increased the tension between my role as a researcher and an actor. For the latter reason, and to minimise the bias that it may introduce to my research, theoretical lenses were used to provide a framework to analysis the context and my interpretations of the context and case study were shared in internal and external forums. Additionally, to avoid any misunderstanding between the various parties the role I was to play was documented in a Project proposal and in other contract documents.

4.3 Research approach

The research strategy adopted is characterised by three key features: interpretive, participatory action research, and longitudinal design.

4.3.1 Philosophical perspective: Interpretive

CBIS development requires an understanding of people and the social and cultural contexts in which they live. An interpretive philosophy is employed here according to the three categories suggested by Orlikowski and Baroudi and illustrated in Figure 4.1 [Myers, 1997, p. 242]. The classification is useful in that it explains the different underlying philosophical assumptions. The approaches are illustrated here as distinct philosophical assumptions, but there is overlap between the different epistemologies [Lee, 1989]. So, though, I adopt an interpretive research approach, I also do so from a critical perspective.

Positivists assume that reality exists independently of our construction of it. Facts and values are distinct and scientific knowledge consists only of facts. Positivist studies, generally, try to prove or disprove theories or hypotheses with the general aim of developing statistical generalisations. Interpretive researchers adopt the position that our knowledge of reality is a social construction [Walsham, 1993] [Walsham, 1995] [Winograd and Flores, 1987] [Boland, 1985] [Boland, 1991] [Lee, 1994] [Myers, 1994]. Interpretive studies attempt to understand phenomena by exploring the meanings people assign to them and the processes through which inter-subjectivity is constructed. Data, collected within IS, is only transformed into information, and then knowledge, through the interpretation and meaning people assign to it and how they act and reflect on that information. Access to information influences knowledge and actions. These very actions influence the use and

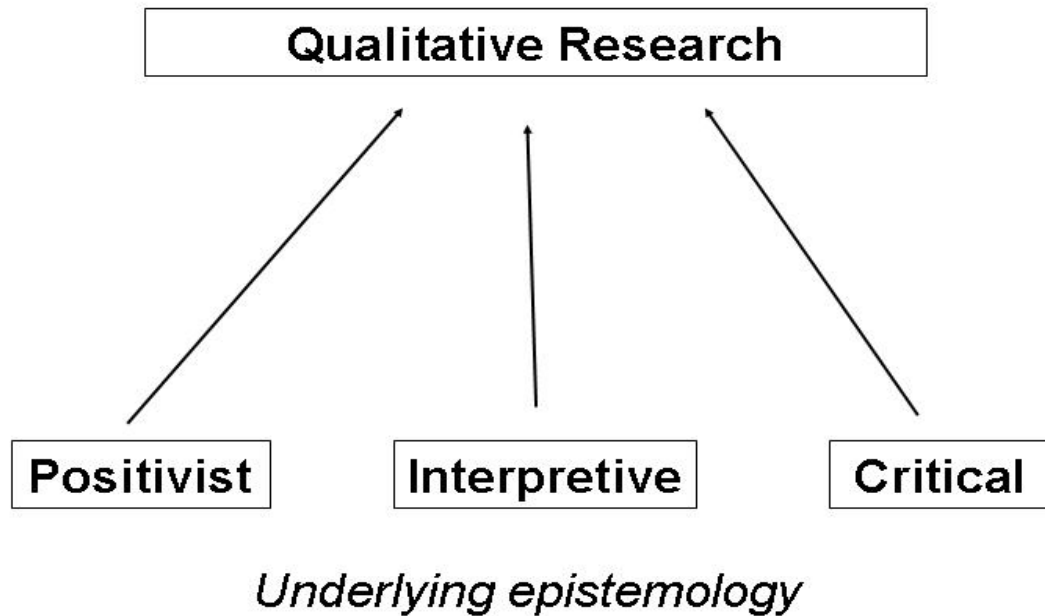


Figure 4.1: Underlying philosophical assumptions

interpretation of the IS and consequently influence its further development. In developing and designing IS it is important to understand the meaning attached to the various data elements that constitute the system and the process of collecting, collating and the consequent use of the data.

The context in which that social construction takes place needs to be examined in order to understand the meanings and interpretations of people. The context in which the community lives is historically constructed and is reproduced through the collective actions of the people. Some of these conditions are restrictive, especially, for example, the position of women and children in most societies. Access to information and capacity to act, based on this information, are an important part of changing these restrictive conditions [Sen, 1999, p. 54/56]. The restrictive conditions, such as social, cultural and political domination, need to be explicitly highlighted in the process of the research. Possibilities for the community to act against, or in line with, those conditions need to be raised. Critical studies explore the structural conditions that are produced and reproduced by people with

the aim of challenging the restraining and alienating structures. This type of research critiques the status quo and seeks to emancipate people from these restrictive structures.

With the emphasis on changing the status quo for children, a Critical Social Theoretical approach was incorporated into the interpretive approach adopted in this case study. A Critical Social Theoretical approach combines the investigation of a practical situation with an underlying theoretical approach, to improve human condition. One of the aims of the process of developing the child-health CBIS was to enhance the capacities of the community to highlight and develop awareness of the situation of their children as a result of the information received. Issues of participation and communication are fundamental aspects in the development of this capacity. Capacities need to be developed that enable community voices to be heard in terms of their needs, interests and expectations for their children. Capacity development must take place multi-sectorally and at different levels. Community members, with the right information and effective capacity, are in a much better position to hold government and other duty bearers accountable, assess the extent to which public programmes are fulfilling the rights of the child and take action as necessary [Jonsson, 2000, p. 3/4] [UNICEF, 2000, p. 37/39].

4.3.2 Research methodology: Action Research

IS design is complex and socially situated and is best studied by addressing a specific problem in a particular context, making changes and analysing the impact of the changes made. My research aimed at increasing the understanding of a community and the development of a child-health CBIS. It, simultaneously, aimed to assist in solving the practical problem of increasing the visibility of the vulnerability of children in the HIS, as well as contributing to scientific knowledge in the domain of how participation and communication is addressed in IS design. The research was collaboratively performed and there was, and continues to be, a cyclical approach to implementing, analysing and evaluating these changes as indicated in Figure 4.2 [Elden and Levin, 1991, p. 131].

Action research has been extensively applied in IS research [Baskerville, 1999] [Baskerville and Wood-Harper, 1998] [Checkland, 1991] [Susman and Evered, 1978]. The approach used in this research includes four major characteristics of IS action research:

- increases understanding of an immediate social situation;
 - simultaneously assists with practical problem solving and expanding scientific knowledge;
 - is performed collaboratively, and;
 - is applicable for the understanding of change processes in social systems.
- [Baskerville, 1999, p. 6/7].

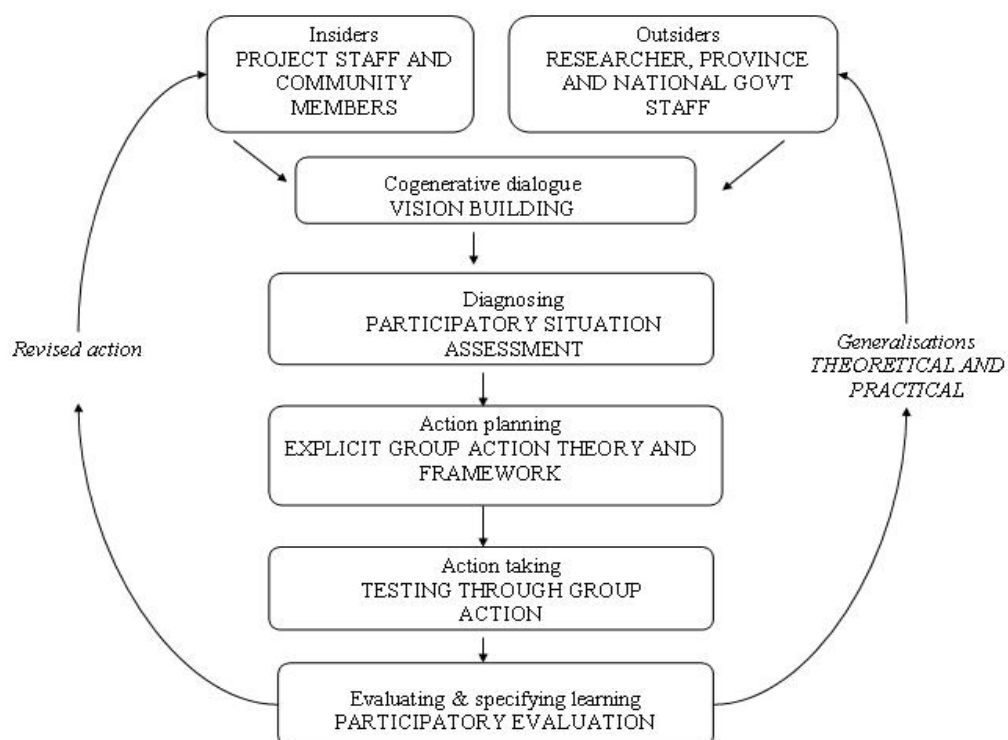


Figure 4.2: Participatory action research model

The particular form of action research which will be used in this research can best be described as participatory action research. This implies a closer relationship between the researcher and the subject and greater participation of 'insiders' than commonly found in traditional action research [Baskerville, 1999, p. 17].

Participatory action research means that all relevant stakeholders do what only researchers usually do. It can be seen primarily as a learning strategy for empowering participants and only secondarily as producing 'research' in the conventional sense. ... The researcher is the linchpin

so that what he or she learns contributes to accumulation of knowledge above and beyond a local, 'context-bound' situation. [Elden and Levin, 1991, p. 131/133].

The research process involved, indicated in Figure 4.2, is an adaptation of Elden and Lewins' model [Elden and Levin, 1991, p. 131]. It also incorporates the five phase cyclical process most prevalently used in action research, namely diagnosing, action planning, action taking, evaluating and specifying learning [Susman and Evered, 1978, p. 588]. The action research framework was adopted as our aim was not just to study and describe an existing situation, but to change it through specific interventions. Each of the steps in the process is examined in detail in Chapter 6

Underlying the action research framework throughout the research process, is a human rights perspective. A human rights approach to IS implies a perspective fundamentally different from conventional systems development approaches. A human rights approach moves beyond a needs-based approach of charitable giving or benevolence to one that views the person as a subject who has claims on other people (the duty bearers¹) who are obligated to respect, protect and fulfil these rights. It recognises the existence of duties and obligations. The implication of this shift is that each person has the right to something (rights claimer) and the right against someone (duty bearer). In IS design, it makes mandatory, the development of an information and monitoring system that enables community voices to be heard in terms of their needs, interests, and expectations. A human rights perspective enables community members to hold government accountable, assess the extent to which public programmes are realising the rights of the child and to take action as necessary. The fulfilment of duties using a human rights approach is crucial, but this depends on capacity. Imperative to a human rights approach is the capacity development of both the duty bearers and the rights claimers.

Participation, as a right in itself, is a fundamental strategy of a human rights approach to IS development. Participation, especially in the context of community, is intricately linked to questions of democracy, power, and asymmetries that exist within communities. Often participation is viewed in terms of extracting knowledge from the community which is of value to the outsider [Puri, 2003, p. 32]. If we replace empowerment with participation in the following quotation it is equally apt.

¹Role players have a role to play in children's lives, but duty bearers are those people who are responsible and obligated to fulfill childrens' rights

Whether empowerment is good depends on who are empowered, and how their new power is used. If those who gain are outsiders who exploit, or a local elite which dominates, the poor and disadvantaged may be worse off. [Chambers, 1999, p. 220]

In general, issues around 'community participation' to a large extent still tend to be seen in terms of how 'communities should participate in our (i.e. externally supported) programme', whereas the issue should be if and how agents of such programmes could be able to participate in their (i.e. community) efforts to improve the situation for themselves and their children [Jonsson, 2003, p. 66]. In this research IS design is viewed from the the perspective of empowering communities to monitor their own status and to claim their rights.

A human rights approach in the development and design of a child-health CBIS was advocated on three different levels:

- Through a partnership with the community and Department of Health, the Project's mission, during the eight years of the programme, was to create a well-being context through child health, maternal health and HIV/AIDS interventions which were co-designed and implemented in a holistic, integrated and sustainable manner. The underlying principles of the partnership were "genuine community involvement using a community development approach where health is seen in the context of total human development". [Bergville District Child Survival Project, 1999a]
- After conducting a monitoring and evaluation workshop, community members wished to participate in the design of an IS which would address their needs.
- The South African constitution and legislative framework also provides a conducive environment for the application of a human rights approach to IS design and development.

4.3.3 Time frame: Longitudinal

The main milestones and events in the design of the child-health CBIS took place between 1999 and 2003 and are summarised in Table 4.1.

The first elements of developing the child-health CBIS commenced with the participatory situational assessment of child health, in November 1999, and with a monitoring and evaluation workshop early the following year. As part of the child-

Year	Milestone
1995	First interventions of the Child Survival Project commence in Okhahlamba. HIS was one of the interventions.
1999	Expansion of Projects activities to the rest of the district. Site chosen for piloting of community child-health intervention. Participatory situational analysis and assessment was conducted.
2000	Monitoring and evaluation workshop conducted.
2001	Mid-term evaluation includes evaluation of the HIS.
2002	Fieldwork on a child-health CBIS commences.
2003	CBIS implemented in June. End-of-project evaluation included evaluation of the HIS. Child Survival Project ends activities and support in the UThukela District.

Table 4.1: Major milestones and activities in TDCSP

health intervention more detailed research was conducted that provided the basis for a monitoring and evaluation component to be developed and also to provide greater insights and understanding into child-health issues in the municipality. More details on the activities are outlined in Table 4.2.

An important aspect in all these processes was the principle that feedback needed to be given whenever any research had been conducted. All participants in the research were invited to a large gathering for the feedback of the overall findings of the research. In keeping with Zulu customs and traditions regarding communication and discussion, the format of the feedback was given through the mediums of drama, poetry, song, dance and posters. A full, written report was also produced and specific feedback sessions, with particular groups such as the Project team, the Community Health Committees and Community Health Workers, were held at a later date to plan the way forward.

The photographs illustrate some of these feedback sessions. In the photograph in Figure 4.3, Gabi Mazibuko, the then UThukela District TB manager for the Department of Health, reviews the role of the Project and the Project leader in the district through a praise poem at the end-of-project evaluation, December 2003. The photograph in Figure 4.4 illustrates poster feedback sessions in the community hall during the mid-term evaluation with research team members answering ques-

Participatory Mechanisms	Mechanisms	What was achieved
Knowledge, and Coverage Survey, Okhahlamba Sub-District, August 1999	Practice Survey,	Baseline data on child health, maternal health and HIV/AIDS.
End-term evaluation, Okhahlamba Sub-District, October 1999		Evaluation of the Project with results fed back through drama and written reports.
Community Assessment, November 1999	IMCI Situation and Analysis,	Baseline assessment on key family care-seeking and health practices, local terminology developed, and gaps identified between community and health facility practices.
Monitoring and Evaluation Workshop, Okhahlamba, February 2000	Bergville,	Community members involved in co-designing a monitoring system with district health staff.
Mid-term evaluation, UThukela District, November 2001		Evaluation of continuance of Project.
Fieldwork on child-health CBIS, UThukela District, 2002 and 2003		Understanding around the meaning of 'well-being' and 'at-risk', what factors/practices contribute to these situations, how the situations can be measured, and who the information should go to and in what format.
Analysis of data and proposed changes in the HIS, OKhahlamba Municipality, April-August 2003		Discussions with district and Project staff and community members on data collected, grouping of indicators, refining of data collection tool and feedback formats.
Implementation of changes in HIS, OKhahlamba Municipality, June 2003		Revised tool, new data elements and changes in format and flow of information.
End-term evaluation, UThukela District, November 2003		Still little use of information, some community data collected, process started but not integrated into DHIS, developed concepts and indicators for well-being.

Table 4.2: Participatory evaluation and situation assessments conducted in the child-health intervention

tions from the public, and lastly, the photograph in Figure 4.5 shows the feedback to all role players and duty bearers of the results of the mid-term evaluation of the Project in 2002.

The process of specifically developing and designing the child-health CBIS com-



Figure 4.3: Praise poem at end-of-project evaluation feedback

menced in 2002. The following major role players were initially identified by the research team, and subsequently, by the research participants themselves, as key to child well-being and development: children, Community Health Committees, Community Health Workers, mothers (including teenagers), fathers, grandmothers, early childhood practitioners, social workers, councillors, traditional leaders, health facility staff and TDCSP staff. These role players and duty bearers were confirmed by the previous situational assessment which had also taken place [Gibson et al., 1999]. A total of 10 interviews, 16 focus group discussions (FGD's) and 1 meeting took place with these role players and is broken down by municipality in Table 4.3.

Some specific gender-segregated groups were identified, such as fathers, grandmothers, mothers and teenage mothers. Members of the research team and community members felt that this segregation would reveal differing opinions. Most group choices were based on the positions the people held in the community. Men formed the majority of participants in the discussions with the Community Health



Figure 4.4: Poster feedback session from mid-term evaluation

Municipality	Interviews	FGD's	Meetings	Total
EMtshezi	1	2	1	4
ENdaka	0	2	0	2
OKhahlamba	9	11	0	20
ENaambithi	0	1	0	1
Total	10	16	1	27

Table 4.3: Research method by municipality

Committees and traditional leaders, but women formed the majority in the discussions with the Community Health Workers, early childhood practitioners and facility staff. In all, women comprised over 60% of people interviewed. Teenagers (13 -19 years) and children (under 13 years) comprised slightly over one quarter of the participants. Participants by municipality is given in Table 4.4².

The data was collected from June to September 2002, as shown in Table 4.5, with

²No data is available on participants in 4 of the FGD's with the Community Health Committees in ENdaka and EMtshezi and for 1 meeting in EMtshezi.



Figure 4.5: Group feedback session at mid-term evaluation

Municipality	Participants	Participants	Total
	Women	Men	
EMtshezi	0	2	2
ENdaka	n/a	n/a	n/a
OKhahlamba	60	36	96
ENnaambithi	4	1	5
Total	64	39	103

Table 4.4: Number of participants by municipality

one additional FGD with children, being held in May 2003. The implementation of the revised IS commenced in the first half of 2003 and an evaluation of the DHIS, which included the child-health CBIS, took place in November 2003.

Fundamental to this longitudinal approach was the desire to operate within existing structures and institutions and to build on activities which were already in place. Furthermore, to really ensure participation, there is the need for capacity development at all levels and this cannot take place within a time frame imposed

Research Method	June	July	Aug	Sept	May	Total
	2002	2002	2002	2002	2003	
FGD	4	9	0	2	1	16
Interview	4	2	0	4	0	10
Meeting	1	0	0	0	0	1
Total	9	11	0	6	1	27

Table 4.5: Dates of fieldwork

by outsiders. Time is also needed to understand the context and to build a trusting and caring relationship between all members. The sustainability of many of the interventions of the Project was borne out by the results of the evaluation, for example, the DHIS at facility level commenced in the district as a Project intervention, but six years later, the DHIS was functioning within the Department of Health without the staff realising that the Project had been involved with the setting up of the system.

4.4 Mode of analysis

In line with the participatory action research framework adopted and the principles of human rights underlying this interpretive approach, the term 'mode of analysis' rather than 'data analysis' is used in this research. From a hermeneutic perspective, the questions posed by the research team to the participants affected the type of data we gathered and the "...analysis affects the data and the data affect the analysis in significant ways" [Myers, 1997, p. 241/242].

A hermeneutic approach to gathering, analysing and interpreting the qualitative data was adopted here and, consequently, is the underlying philosophy behind the interpretive approach which was adopted. It was used as a way of understanding the meaning attached to data and making sense of the relationship between people, their environment and the IS. At community level there were different, often contradictory, views on what was needed in the IS and the purpose it served. The challenge faced was in the interpretation of the many viewpoints to the design of IS and how the consequent changes in the IS affected those very viewpoints.

Both the data collection and analysis process were iterative, evolving and connected in a cyclical manner. It is a continuous process, as the assessment fits into

the analysis which shapes the action and informs further assessments, and so the cycle continues. The participatory modes of analysis, such as interviews, discussions, feedback from presentations and writings, as well as insights from theoretical work and other empirical work, contributed to the data collected and further analysis and interpretations.

After the preliminary round of fieldwork was conducted in 2002, regular meetings were held with the research team to review the results from the field work, to discuss issues and gaps and to reflect on the process. In this manner, clarification over the meaning of the terminology and concepts, which were often culturally informed, was obtained. For example, initially children had not been included as a separate group to be interviewed as it was felt that they would be part of other groups. This was later felt to be an omission and specific comments and inputs from children were subsequently obtained. In a preliminary review of the data from the focus group discussion with the children, one of the signs to indicate a child who was 'at-risk', was that a child would be 'respectful'. After obtaining clarification from the children on what 'respectful' meant in this context, it was understood to mean 'shy and introverted'. For the children in the focus group discussion this behaviour is similar to children who avert their eyes and remain quiet when showing respect to elders.

The raw data, from the preliminary round of data gathering was entered into an Access database. The fields in the database were generated and based on the themes used in the focus group guidelines, such as the definition of 'at-risk', conditions for 'at-risk', measurement of 'at-risk' and who the major role players and duty bearers were. Lists of the terms used, and their frequency, in each of these fields were generated from the database. In a one-day meeting with the research team (July 2002), these lists of terms were categorised into groups of common terms, for example, under the grouping *Active and plays*, the following terms were included: active, asks questions, not withdrawn, plays, shows life, free to share with other children and playful. Table 4.6 shows some further examples of the grouping of the terms for the field 'definition of well-being'.

To develop indicators for these terms, another meeting was held (December 2002) with district health staff, health facility staff, Community Health Committee representatives and staff from the Project. This meeting placed the groupings into different levels - child, household and community. The photographs illustrate

Example of Category	List of terms from field work
Active and plays	active, asks questions, not withdrawn, plays, shows life, free to share with other children, playful.
Nutrition and breastfeeding	feeding, solids at nine months, nutritious food, well-nourished, vegetable garden, food.
Care seeking	takes child to clinic when sick, visits clinic, weighs child regularly, immunises child, practises good behaviour,
Happiness	cares, makes appropriate and timely decisions.
Psychosocial development	happy, ever-smiling child, "nice face even if you warn the child".
Care	social, spiritual, mental, psychological.
Hygiene	looked-after, care, time with child, support.
	hygienic practices, clean yard, washed.

Table 4.6: Examples of groupings for the definition of 'well-being'

how this was done through a process of writing all the groupings, such as 'Active and plays', 'physical health' etc, onto cards and then placing them at the appropriate level on a large sheet of material which had been stuck onto the wall. This classification was useful in terms of identifying where the data could be collected. The photograph in Figure 4.6 shows how cards, with the respondents answers, were placed on a large sheet to help define indicators. The photograph in Figure 4.7 illustrates the process to help define indicators, their source and frequency of collection. The indicators for these groups were discussed and, where possible, more precisely defined, based on the 'measures' which had been collected from the various respondents in the field work. The outcome of this process is elaborated on in Chapter 7.

Presentations were made by me and other research team members to the respondents of the research, academic audiences, national child health and donor meetings. Through participation in academic seminars and conferences, the links with the underlying principles of the research undertaken, such as participation, capacity development and communication, with possible theories and theoretical approaches emerged. Furthermore, reviews of papers written and presented at conferences [Byrne and Sahay, 2003b] [Byrne, 2002] [Byrne and Sahay, 2003a] [Byrne, 2004c] [Byrne, 2004b] [Puri et al., 2004] [Byrne, 2004a] [Byrne and Gregory, 2004], exposed my ideas and thoughts to a national and international audience and provided useful insights and further interpretations. Discussions with colleagues and



Figure 4.6: Defining indicators from field data

my supervisors clarified many of ideas and facilitated the connection of the ideas with contemporary debates on these issues. Through additional reading of IS literature, these connections were further developed. As mentioned in Chapter 2 the theories used were not predetermined from the outset, but increased in relevance as my own exposure to the contemporary literature increased. Through initially starting the process with the underlying principles of human rights, participation and capacity development, the lenses of Structuration Theory and Critical Social Theory assisted with the better-articulation of the context, process and output of the research. Additionally, this exposure afforded alternative lenses through which to view and interpret the research - an important tool, considering I had been working with the Project for a long period of time and had probably grown accustomed to approaching the Project from an angle with which I was familiar. The photographs in Figure 4.8 and Figure 4.9 show the presentation of the research through a poster presentation at a donor meeting. Feedback and comments from these presentations assisted with further analysis by bringing more interpretations to the table. Com-



Figure 4.7: Participatory analysis of data

community feedback sessions helped clarify some of the interpretations made by the research team and also assisted with realistic action planning. The photograph in Figure 4.8 shows three posters depicting the activities of TDCSP at a donor meeting and the photograph in Figure 4.9 illustrates, in more detail, the poster reflecting the development of a child-health CBIS.

In summary, the various modes of analysis utilised in this research were:

- the use of theory to inform thinking and adaptations of that theory to provide further insight and meaning into the data;
- the conduct of interviews with key people in one-to-one settings and in group analysis situations;
- feedback of findings to, and discussion with, major role players and duty bearers at local and higher levels;
- feedback from presentations at conferences and meetings at national and international level;
- discussions with other researchers and academics, such as supervisors;



Figure 4.8: Three posters depicting TDCSP activities

- feedback and comments from writing for various audiences, such as the non-governmental sector, implementers of government strategies and policies and academics, and;
- insights achieved by exploring the conversation between theory and empirical work.

The output of the modes of analysis is given in the rest of this thesis on two levels. On the one level, there is a detailed account of the iterative and recursive processes undertaken in the development and design of the child-health CBIS for the OKhahlamba Municipality. On the other level, the process of using lessons learnt, on a practical and theoretical basis, from this localised setting, to inform future IS design in other settings and to become part of the National Health System, are explored.

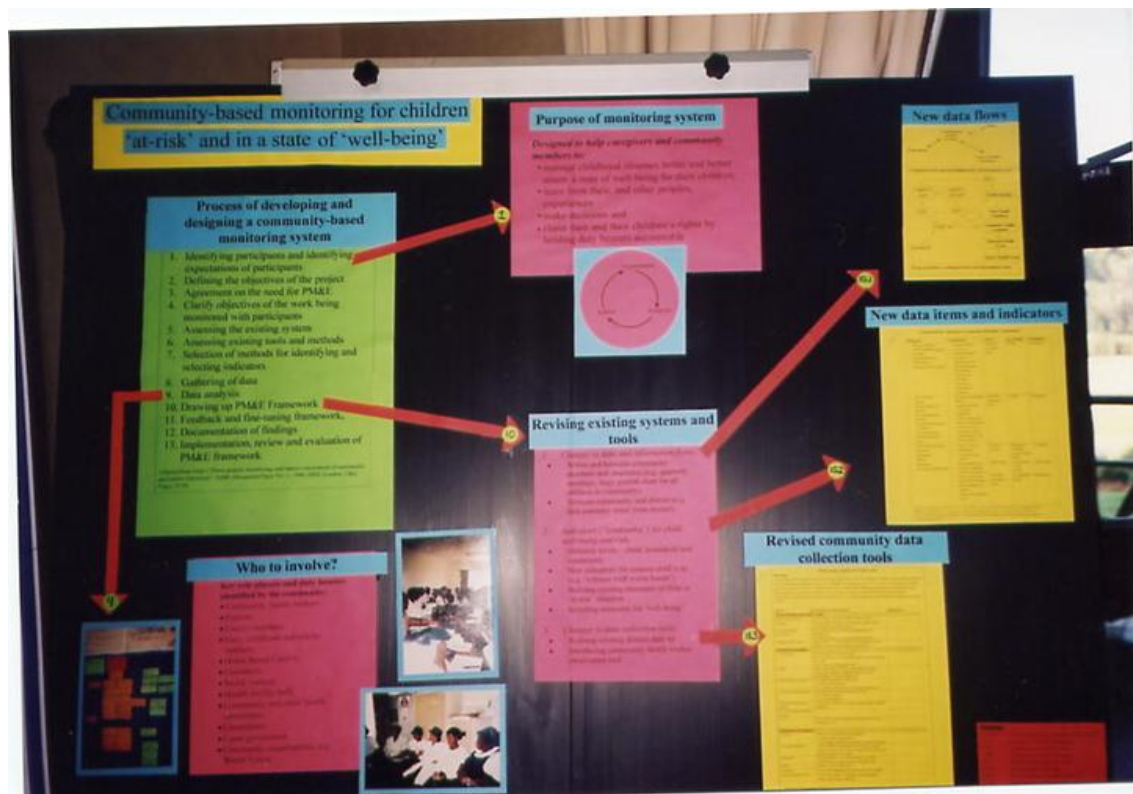


Figure 4.9: Poster reflecting the CBIS development process at donor meeting

4.5 Ethics statement

All participants in the research agreed that it would be beneficial for them to be part of the research. Acknowledgement of their contribution is given in all work produced from their fieldwork. The identities of the participants in the interviews and focus group discussions is protected, unless the individual participant requested otherwise. In cases where the participant's identity was difficult to protect, such as Project leaders or managers, who were few in number, the participants were made aware of this difficulty. All the findings and products of the research have been regularly shared with participants for their information, comment and contribution.

Given the busy schedule and pressures of daily life in the community, the research was conducted, as far as possible, to minimise interruptions. Discussions were held close to where people worked or lived. Groups were formed, based on existing structures and networks, so that the discussions could continue after this particular episode of research finished. For example, the children, who formed the respondents for the focus group discussion, are part of an orphans group that has

been established in the area. This meant that issues that were raised in the discussions could be followed-up and actions could be taken at a later stage if needed. The focus group discussions with the Clinic Health Committees resulted in the committee members being trained on child-health, as this request was the outcome of the focus group discussions. This strategy, hopefully, will also contribute to the sustainability of the CBIS.

The people who conducted the fieldwork volunteered to do the work in addition to their normal workload. Their participation depended on the time and resources they could spare. All members of the research team agreed that the results of the research would also be beneficial to them, for their own work.

In terms of culture and language, all the fieldwork was conducted in the language-of-choice of the participants and recorded in culturally-acceptable manners. Most of the discussions took place in isiZulu. Some of the discussions were audio-taped, others were written on flip chart paper or standard A4 paper and, in some cases, photographs and videos were taken. All groups were given an explanation for the research and all feedback of all the results of the research occurred at a later date.

Chapter 5

Okhahlamba: social and political processes

A brief account of the case study, OKhahlamba Municipality in the UThukela District, was given in Chapter 1. In this chapter, focus is placed on how the context of the case study affected the process of design, development and, ultimately, the implementation of the child-health CBIS. The restructuring of the health system, the transformation of local government, and social traditions and culture, are important aspects of this context. The implications of these aspects, within the structuration process of social life on the IS design, are then described¹.

¹The content of this chapter formed the basis of the following paper: E. Byrne. Development through communicative action and information system design: a case study from South Africa. South African Computer Journal (SACJ), 32:25-33, 2004b

5.1 Introduction

An often cited reason for failure of ICT's in developing countries has been the over emphasis on the technical transferability of the information technology component, with little emphasis on the social context in which the IS is being applied [Hirschheim and Boland, 1993, p.xii]. If the primary focus of IS design, or revision of an IS, is emancipatory, as is the case here, then there is the need to understand the social context from which the improvement is sought. This is especially problematic when adapting an IS from a well resourced economy (or section within it) to one lacking such resources. To circumvent such pitfalls the exploration of the broader social context in which people are immersed is argued for by many authors in the IS field, rather than confining the exploration of the context to the organisation in which the IS is being designed. Walsham and Han [Walsham and Han, 1991, p.79], commenting on the work of Poole and DeSanctis, argue for the need to look at the broader organisational context if further empirical work on the group decision-support system is to be conducted. Korpela et al. [Korpela et al., 2004, p.459] note that "Social theories other than activity theory should be applied to the organizational, financial, and wider societal contexts of activities."

Most definitions of IS ([Avison, 1997]; [O'Brien, 2003]; [Korpela et al., 2004]) explicitly or implicitly assume an organisational setting. As Kanungo [Kanungo, 2004, p.408] notes, "the definitions imply the existence of a formal IS management structure, a certain pattern of information system use, and a specific notion of utilities associated with information and associated technology." A broader contextual understanding of the environment in which people live is especially relevant when we move outside an organizational context.

In explaining the context, there is the need to move beyond the vagueness in which the term 'context' is often used. It is in this respect that Structuration Theory is a very useful analytical tool and can be used as a meta-theory which helps explore the setting and social processes within that setting. The design and development of a child-health CBIS took place in one municipality in the UThukela District of KwaZulu-Natal South Africa. Many authors [Walsham, 1998] [Walsham and Sahay, 1996] [Jones, 1997] [Rose, 1999] [Orlikowski, 1992] [Orlikowski and Baroudi, 1991] [Orlikowski and Robey, 1991] have recognised the importance of structure in shaping IS design and use. Exploring the context in terms of structures and its modalities, Structuration Theory not only allows us to recognise the need to

challenge constraining structures, but also to build upon the enabling ones if changes in that context are to be made.

This chapter explores how using Structuration Theory, as a lens through which the context is viewed, can assist with a more systematic description of the context and help illuminate opportunities and potential challenges. This chapter's focus is placed on how the broad social, economic and political structures in a particular context affected the process of designing a child health CBIS. In understanding the context in which IS is designed Structuration Theory is useful in that:

- It allows the researcher and/or the practitioner to explore the context not from the traditional setting of an organisation, but to readily incorporate the broader societal and political environment in which people are situated, and;
- That, an IS designed to be emancipatory needs to change existing structures to realise this objective. This will require an understanding of existing structures and the social processes which create, and recreate, these structures.

Accordingly this chapter continues with an exploration of the political and social processes taking place in the context of that case study and how an understanding of these processes enabled opportunities and challenges for IS design to be identified. Two key aspects of the structural conditions which address the exclusion of children from the health services and which, consequently shaped the process and outcome of the design and implementation of the child-health CBIS, are outlined in this section. The first aspect, namely the restructuring of health services, provided an opportunity for change and reflection on the current role and function of the IS, whilst also providing an understanding of the exclusion of segments of the population. The second aspect, namely social traditions, again provided an understanding of the position of women and children in society, which impacted on IS design as well as presented some challenges in the design process.

5.2 Restructuring the health services

The Department of Health has been guided, in the restructuring of the health services after 1994, by a broader process of local government transformation which defines the powers and responsibilities of local government. The reason for this linkage is twofold: (a) the constitutional mandate of municipalities to render 'Municipal Health Services'; and (b) the decision that municipalities are the ideal sphere

of government to take responsibility for the governance of health districts. [Pillay et al., 2001, p. 9]. An understanding of the restructuring of the health services, therefore, necessitates an understanding of the transformation of local government. This section explores the transformation of local government, the movement towards a DHS and the changes and challenges that surfaced in this process.

5.2.1 Transformation of local government

The Government of South Africa since 1994 has had the difficult task of uniting the previously 'decentralised' apartheid regime into a more equitable system whilst, at the same time, establishing a 'decentralised' government that was accountable to its people. Decentralisation can mean different things to different people, but a common view which can be expressed in the phrase 'bringing government closer to the people' is that decentralisation may be a key ingredient in making government more accountable to its citizens [Wittenberg, 2003, p. 4].

The transformation, at a regional level, has been relatively easy and nine provinces were formed and new functions were allocated to the provinces under the constitution. Transformation, at the local tier, has been a more time-consuming process. It started in 1993 with the creation of a set of 'negotiating forums', with the Local Government Transitions Act. "These fora effectively became interim local authorities. Their task was both to deliberate on the appropriate post-apartheid shape of the municipalities and to run the municipalities until this post-apartheid infrastructure was in place." [Wittenberg, 2003, p. 33] Local government elections for Transitional Local Councils (TLCs) and Transitional Metropolitan Councils (TMCs) were held in 1995 and put an end to the previous interim structures. The 'transitional' period came to an end with the 2000 municipal elections. The framework for local government is contained in the constitution (passed in 1996) and in the Municipal Structures Act of 1998. There are three types of local government: type A (Metropolitan Councils), type B (Local Councils) and type C (District Councils). Furthermore, the Local Government: Municipal Demarcation Act of 1998 had provided for the re-demarcation of all municipalities within the country. This led to a rationalisation of the 843 municipalities down to 284 municipalities: 6 type A, 231 type B and 47 type C municipalities. The districts were also re-demarcated. One consequence of these transitions was that, as of 1995, South Africa had 'wall-to-wall' municipalities. [Wittenberg, 2003, p. 24]

Wittenberg summarises [Wittenberg, 2003, p. 34] the current intergovernmental systems as comprising four tiers, except in the metropolitan areas where there are only three:

1. National government has responsibility for security (army and police) and national economic policy as well as for overall direction of the social service departments.
2. Provincial government administers the major social services: education, health, transfer payments (e.g. social pensions and child care grants).
3. District councils, in some cases, organise water and sewerage reticulation and other bulk infrastructure, while in other cases, they do not have a clear rationale. They act as municipal service providers of last resort, if their constituent municipalities do not have the capacity to fulfil their mandates.
4. Municipalities have a key role to play in the provision of basic services, in particular water, sanitation, refuse removal, electricity, town planning and so on.

Health, in the broad sense, is impacted on, therefore, by all levels of local government.

5.2.2 Restructuring the health services

As mentioned earlier (see Chapter 1, Section 1.2), the PHC approach to health delivery was adopted as a conceptual model for health-care planning and health systems development, but a clear policy on the structure and organisation of the health system was also required. The Department of Health in South Africa adopted the model of the DHS to do this. The National Health Policy for a DHS was first documented in the early 1990s through the African National Congress Health Plan. Subsequently, it has been outlined in a number of other documents such as the Reconstruction and Development Programme and the White Paper for the Transformation of the Health System. The DHS policy was implemented throughout the country from 1995 onwards [McCoy, 1999] [Haynes and Hall, 2002].

In terms of the delivery of health services, the constitution [Government of South Africa, Section 156(1)] states that local government is responsible for the delivery of

'Municipal Health Services'. The constitution does not, however, define 'Municipal Health Services'. There has been much discussion and debate on what constitutes 'Municipal Health Services' and health-related matters that are subsumed under this term, including water and sanitation services, preventive child-health services, and refuse and solid waste removal [McCoy, 1999, p. 114]. In July 2002, the Minister and the Heads of Health in the provinces (this group is abbreviated as MinMEC), agreed that 'Municipal Health Services' should be narrowly defined as 'environmental health services', and this was confirmed in Cabinet discussions on 9 October 2002. This narrow definition of 'Municipal Health Services' means that mobile clinics, clinics, Community Health Centres and District Hospitals will remain the constitutional responsibility of provincial government. National Health Policy, however, still appears to favour the long-term vision of local government being responsible for the full package of District Health services (up to and including District Hospitals) [Haynes and Hall, 2002, p. 85/86].

Within the DHS, the management of the health services is the responsibility of the District Health Management Teams under the leadership of a District Manager. The management team manages all PHC services and facilities, including the district hospital, within the district. For this to happen, there were two requirements: (a) Health districts need to establish management teams with the technical and managerial capacity to manage a wide and complex range of PHC services and (b) an appropriate degree of authority and freedom must be transferred to the management teams, so that they can plan, implement and manage their services, and facilities [McCoy, 1999, p. 115]. As will be discussed in the next section, both these requirements have not yet been fully met in all districts.

The constitution, the re-drafted National Health Bill and the various local government Acts mentioned, all note the need for community participation through various structures. Within health, such structures comprise Community and Clinic Health Committees and Municipal and District Health Forums. The extent to which these structures are operating varies within and between provinces. However, there is still the need to develop local leadership in order to create an active civil society.

Indeed, one of the key ingredients which is currently missing from the system, is a lively and functioning civic movement that can hold local officials to account. South Africa had a lively civic movement during the struggle against apartheid. Unfortunately, the leadership of this move-

ment was absorbed either into government or went elsewhere. [Wittenberg, 2003, p. 50]

5.2.3 Changes and challenges in the restructuring process

Delay and uncertainty in each of the three restructuring exercises mentioned above led to the re-shuffling of departments between municipalities. The re-shuffling is not, as yet complete. In 2002, provincial governments issued a set of determinations on the allocation of responsibilities between districts and type B municipalities [Wittenberg, 2003, p. 34]. Haynes notes that,

The lack of clear policy direction has resulted in a wide variation in establishing district and sub-district health management teams. . . . At the health sub-district level there are variations between the provinces and even within the provinces. Certain provinces have made permanent appointments in some sub-district leadership posts, while their colleagues in similar posts are still working in an acting capacity. [Haynes and Hall, 2002, p. 94]

The first task to be addressed by the provincial managers in the Department of Health was the demarcation of the health districts.

Two fundamental criteria were used for this process: these boundaries had to be coterminous with local government boundaries and contiguous. Other issues that provinces took into consideration were: financial viability; existing health services; transport routes; sites of economic activity; and geography. [Pillay et al., 2001, p. 7]

By 2002, all provinces, with the exception of the Western Cape, had health boundaries coterminous with the local government boundaries [Haynes and Hall, 2002, p. 89]. As McCoy notes,

A massive and complex rationalisation of the 14 apartheid health departments has been taking place since 1994. There is now a single National Department of Health and nine provincial Departments of Health. In some provinces several former homeland administrations have had to be amalgamated. . . . Administrative fragmentation has therefore been

overcome, laying the foundations for the establishment of the DHS. [McCoy, 1999, p. 112]

With the new demarcation, successful functional integration was achieved in many provinces. In some provinces, joint District level planning structures with local government and Department of Health have been formed. This process has not been without its difficulties. The main barrier to overcome was the disparity in salaries and service conditions between health workers, employed by provinces and municipalities, and between municipalities of different grades. Additionally, all health workers in a District should be employed by and report to a single health authority, which was difficult given the pace of local government reform [Pillay et al., 2001, p. 7].

A number of other challenges still face the Department of Health in the restructuring process. Some of the main issues are:

- There is lack of clarity around the distinction between 'governing' and 'management' within the health district.

Governing covers local political and community representation as well as the oversight function of the local delivery of health services. The management structure is responsible for providing the technical input and health expertise to planning, as well as for the day-to-day management of PHC services, up to and including district hospital services. Despite these broad distinctions, inadequate attention is being paid to what this actually means in practice. Adding to this confusion is the loose use of the term 'local government' which can include both elected politicians (providing 'governing' functions) as well as salaried officials (providing 'management' functions). In other words, the term 'local government' is often used to mean both the 'governing' and 'management' aspects. [McCoy, 1999, p. 114]

- As mentioned above, for the effective management of the DHS, the District Management Team needs to have management skills and effective authority. Many health districts still lack a well-established district health management structure and have recently, in the last two to three years, appointed a District Manager. McCoy notes that the delays in the establishment of the management teams

... are related to the delay in resolving the local government issues ..., as well as to the rigidity of the Public Services Commission which has made it difficult for provincial departments of health to adopt a more flexible approach and rapid pace in establishing district health management structures. [McCoy, 1999, p. 116]

Management skills is another issue which affects the effectiveness of the District Management Teams

Another reason why district management training has not achieved its full potential is that district level managers have not been given the freedom and autonomy to plan and manage their services. Some provincial managers continue to operate within the more familiar top-down and hierarchical style which undermines effective decentralisation and frustrates district health workers who feel trapped by being given responsibilities without equal authority to carry out their responsibilities. [McCoy, 1999, p. 116]

- Another challenge faced, which McCoy points out, is that many local government institutions:

... are small and without the human, infrastructural and financial capacity to adequately and effectively manage PHC services. Because technical capacity tends to be poorest in those areas with the poorest health services and the worst health status, decentralisation may aggravate inequitable health care delivery. [McCoy, 1999, p. 114]

- Lehmann and Sanders [Lehmann and Sanders, 2002, p. 120] show that there has been progress in addressing the human resource issue in South Africa. This progress includes:

- A Human Resource Strategy for South Africa, which addresses human resource issues throughout the country and looks at enhancing the skills and capacity of employees in the public sector.
- The draft National Health Bill which includes a chapter on human resources.
- Some progress has been made in the decentralisation of human resource functions to the districts.

However, there are also challenges to be addressed in this respect. HIV/AIDS imposes a double burden on the health sector, through increases in the workload on health staff, as well as impacting on the health workers themselves. Other challenges include the availability of appropriate clinical and management skills and the migration of health-care workers to the private sector and to other countries. The changes in the health structures, additionally, imposes the need for management skills on many health workers who were previously only involved in clinical practice. "These are skills for which few of the newly appointed district, sub-district and programme managers received training, resulting in a wide gap between existing and required job competencies." [Lehmann and Sanders, 2002, p. 122]

5.2.4 Situation of UThukela District Health Services

The restructuring process meant that, after 1994, the Province of KwaZulu-Natal had the difficult task of bringing together the administrative and management patchwork created during apartheid. Formerly, the Natal Provincial Administration was responsible for hospitals, curative care and limited preventive care in its areas, whereas the KwaZulu administration rendered all services in all areas under its jurisdiction. The Department of National Health and Population Development administered vertical programs such as family planning, environmental health, TB control, mental health and school health (sexuality education and HIV/AIDS prevention). Local authorities (municipal) offered a limited range of preventive and curative services.

As McCoy notes, [McCoy, 1999, p. 116]

Developing the DHS in KwaZulu-Natal, for example, was difficult because it was unclear who was responsible for making policy decisions about setting up the DHS. Although the regional director was responsible for over-seeing district development in her area, she fell under the line management of the provincial Directorate for Hospital Services, which only partly dealt with DHS development. The responsibility for clinics, hospitals and human resources fell under three different Chief Directorates, making it difficult for district staff to know who to refer to. The health district as an integrated unit for the delivery of PHC did not appear to be central to the provincial health structure.

In spite of South Africa's apartheid policy, and the restructuring of the health services, a groundwork of well-equipped and staffed clinics does exist in the UThukela District as shown in Table 5.1².

Municipality	Clinic	Mobile Service	Hospitals
EMbabazane	5	1	0
EMtshezi	5	6	1
ENdaka	6	3	0
EMnambithi	11	10	1
OKhahlamba	6	3	1
Total	33	23	3

Table 5.1: Health facilities in UThukela District by municipality

In addition to the health facilities in the OKhahlamba Municipality indicated in Table 5.1 there is one nutrition centre (initiated by World Vision) in the Sub-District that is situated near Emmaus Hospital. All clinics in the municipality provide comprehensive care and have established referral linkages with Community Health Workers. Most facilities are equipped with radio or telephone, although communications are often interrupted or damaged by the frequent storms in the area and the mountains can interfere with reception. Clinic workers have professional nursing qualifications obtained mainly in Regional Hospital settings and based on the biomedical model (curing of disease/illness). In the last six years additional training on the management of children in a PHC setup has been carried out.

Traditional healers are present throughout the district, with the number of clientele consulting them varying by geographic area. There has been some contact between the Department of Health structures and local traditional healers, but less with traditional healer's associations. Workshops have been organised together with interested traditional healers around HIV/AIDS, and a home-based care program for people with AIDS has been started in EMnambithi Municipality with traditional healers. Home-based care-givers are also present throughout the district. There are four School Health Teams in place, but they are unable to cover more than a fraction of the schools in the area and are currently not linked to any facility or referral service.

Given all these resources, there still some gaps in the health services. Some geographic areas, within UThukela District, such as MaBlessing, have inadequate

²Source: SAHR 2002, p499

access due to distance from services (over 10km of mountainous 'climb' to the nearest clinic). Some facilities are over-crowded while others remain under-used: mobile services, which provide preventive care are under-used; the management of facilities is inadequate, leading to inefficiency; and mothers are still uncertain about when to seek curative assistance, leading to unnecessary visits to health professionals [Gibson et al., 1999].

Sometimes district hospitals are not able to give the required support to clinics, especially in dealing with obstetric emergencies. This is related to a high turn-over of physicians, and a lack of skills among the many junior doctors that staff the hospitals. There are incidences in which the hospital cannot deal with eclampsia or do an emergency cesarian section. Due to a separation of hospital and PHC services in the past, along with a hospital service focus, links between hospitals and PHC services remain weak. Recently, the shortages of trained doctors and nurses is becoming particularly acute. As with other districts, many nurses are taking jobs overseas and their positions are not being filled. The staffing gaps increase the workload of the remaining health facility staff, and doctors and nurses in turn, seek alternative employment [Lehmann and Sanders, 2002, p. 129].

The restructuring period has also had impacts, particularly important to KwaZulu-Natal, on the position of chiefs (*amakhosi*) and communal land. The *amakhosi* embarked on a limited campaign of refusing to cooperate with local government structures which delayed some of the local consultation processes [Wittenberg, 2003, p. 49/50]. Some agreement over their role has been achieved, but the debate is still ongoing.

The District Health Forum comprises representatives from the five municipalities and liaises with their respective District Management Team. The OKhahlamba Municipality established their Municipal Health Forum in 1994 (then called the Bergville District Health Forum). Although they have been operational since that time, they are only now formalising their structures and receiving training from the National Progressive Primary Health Care Network regarding their role and duties. The rest of the municipalities did not have Health Forums operational by the end of 2004. The District Manager for UThukela, with many other members of her management team, was Acting for several years, causing insecurity amongst officers about the stability of their positions.

5.2.5 UThukela District Health Information System

As was the rest of the health services in South Africa in the apartheid era, the Bergville Health Services was deeply fragmented. The Bergville Health Services had five Health Authorities with, consequently, five sub-DHIS. HIS data from the five services were, for the most part, incompatible with one another and could not be aggregated or compared. Uncertainty, on size of the target population, meant coverage rates could not be accurately calculated and the HIS, contained large quantities of data on service activities, that were rarely used. The common complaint of inadequate information for the running of an effective managerial process was often heard.

The present DHIS was initiated as a Project intervention in OKhahlamba Sub-District in 1996 by the Bergville District Child Survival Project and has now grown to encompass the whole of the UThukela District. The DHIS is completely managed by the Department of Health. The current goal for the DHIS in the UThukela District is: *A flexible District Information System that is able to deliver accurate, current and integrated information, and give constant feedback to all levels and sectors, enabling decision-making for quality of care.* One of the major strategies for inscription is capacity development. Within the district, the objectives for this strategy are:

- providing training and input from HIS consultants, where necessary;
- assisting community organisations, committees and Health Forums in exploring and defining their information and research needs, and;
- assisting various sectors of the Health Department in exploring and defining their information and research needs.

The information flow designed for the UThukela District is shown in Figure 5.1:

In the district the dedicated staff for the implementation of the DHIS is the District Information Officer. Facility Information Officers are nurses or clerks, at facilities, who have been assigned the IS tasks in addition to their normal duties. The DHIS was reviewed as part of the Project's mid-term evaluation for OKhahlamba Sub-district in November 2001, and again in the end-of-project evaluation in November 2003, for the whole district [TDCSP, 2001] [TDCSP, 2004].

The end-of-project evaluation confirmed the very strong 'data culture' that exists in the UThukela Health District. Health workers submit relatively large quan-

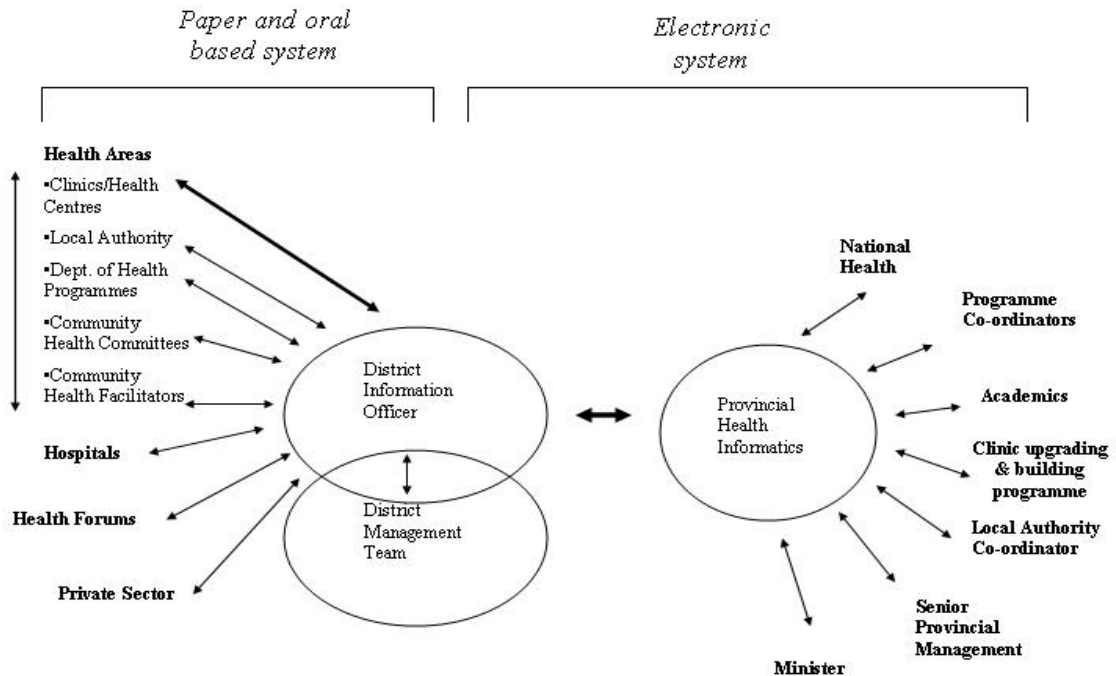


Figure 5.1: Proposed information flow for the UThukela District

tities of data to the district office. A standard clinic tick register is operational in all facilities (though it still remains fairly complex and its value should still be explored). A number of the facility staff and Department of Health officers co-designed the data collection tools and agreed on the minimum data set. The information flow is effectively implemented for PHC data. The duties of a Facility Information Officer have been assigned to a person in most of the facilities in the whole district, though with staff attrition and movements, many officers, currently responsible for analysis of data, have not been trained. Each facility (Hospital and Clinics) submits a monthly report to the District Information Officer. There is 100% response from all the facilities in the district and the data is correctly entered into the IS. A manual system of data collection and collation is in place up to district level. However, in the evaluation, there was little hard evidence that the data is used extensively for decision-making or as information for management. Many of those interviewed felt that the data in the report was not very useful or relevant to the work they were doing. In the final evaluation of the Project it was noted that “... there are

some positive actions, but these are not integrated - one comment was that some 'lights are on but it is not sustained and integrated. The question to be addressed was: How to turn all the lights on and make it work?" [TDCSP, 2004, p. 78]

At district level, the data is entered into the DHIS software and, until 1999, the District Information Officer produced regular quarterly and annual reports for the district. Due to the departure of the District Information Officer, and this position was not filled until September 2003, this is currently not the case for the UThukela District. These reports, when produced, were sent to the Department of Informatics, Provincial Department of Health, District Management Team, programme and team leaders and the District Development Forum. The District Council also has data on water supply, sanitation, income and gardens at ward level. The Environmental Health Officer also has data and this is forwarded to the District Information Officer. The environmental data includes data items on rubbish pits, sanitation and food samples. Through TDCSP, an orphans' register is also available at ward level in the OKhahlamba Municipality. However, all this data is not integrated into the DHIS.

Information is flowing well between the various programmes within the Department of Health, though in an interview with the recently-appointed District Information Officer during the end-of-project evaluation, I was informed that not all the programmes are using the data and information effectively. Data at facilities was often used to develop indicators that are not population based. As a result, coverage, or an indicator related to catchment areas was not developed, and as such, progress towards objectives could not be measured. Information from the facilities is inconsistently and unsystematically shared with the Community Health Committees or the District Health Forum. Where shared, the dissemination of the information is verbal, as the facility staff, interviewed in the mid-term evaluation, believed that the Community Committees or Forum would not understand graphs and written reports if the information was shared in this manner. No regular or defined information is disseminated from the community structures, through the Forum or Committees, to the health facility. In effect, therefore, the information (or actually data) flows are as illustrated in Figure 5.2.

5.2.6 Community-based information

Community Health Workers have been employed in the UThukela District since 2000 and 65 through the Child Survival Project since its inception in 1997. Community

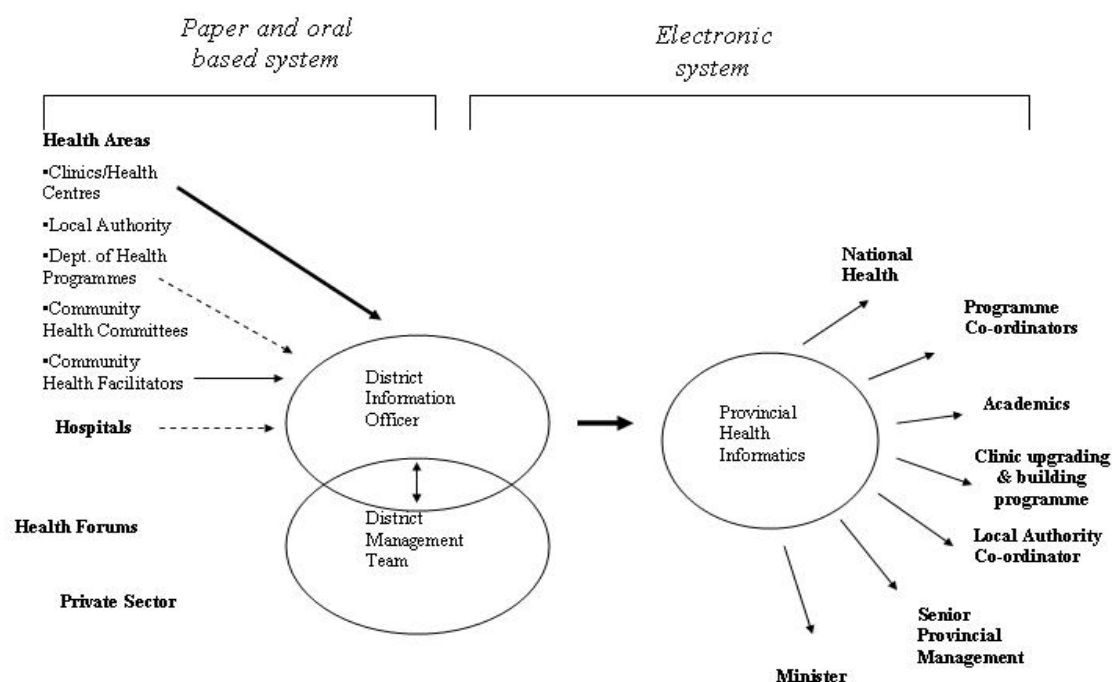


Figure 5.2: Actual data and information flow for UThukela District

Health Workers in the OKhahlamba Sub-District have been trained and collect data on growth-faltering, children at risk, low birth-weights, home deliveries and deaths by age and by cause. Community Health Workers collect data in the OKhahlamba Municipality on growth - faltering, children gaining weight and children who have lost weight, children without a 'Road-To-Health Card', children at risk and the number of referrals. In addition, the following data is also routinely collected: number of births, place of delivery (at facility or at home), whether the pregnancy was full term or not, deaths by age, by cause, location, whether the children were seen at a facility before death and whether the children were on the 'at-risk' register. Community Health Workers in the rest of the district do not collect the same data. All the Community Health Workers collect data on an annual basis for the 'working-for-water' programme. The data items include the number of households with a toilet, water source and the number of rubbish pits.

At a monthly meeting, the Community Health Facilitators collate all the data they have received from the Community Health Workers they supervise and send

this to TDCSP. The summary is sent to the District Information Officer and gets reported in the DHIS reports. The summary includes data on growth-faltering, children gaining weight and children who have lost weight, children with a 'Road-To-Health Card', the number of referrals and children at risk. The Community Health Workers, with the assistance of the Community Health Facilitators, give feedback to the community through village health days, where song, dance, drama, role-plays, pie graphs and bar charts are used. The results of the growth monitoring and promotion and immunisation status of the under-five-year-olds are reported back on using the Triple 'A' approach of 'Assessment, Analysis and Action' at community level. The attendance at the village health days is improving all the time with mothers and care-givers making up the majority of the numbers. It is also encouraging to see the number of men increasing and efforts to include them more actively are continually being explored. In some areas, the Community Health Workers attend the Health Forum meetings and give verbal feedback to the Forum members.

With the expansion of the Community Health Workers' programme to the province, the Community Health Workers have had to undergo a 12-week training course and, as a result, very few village health days have taken place in the last year. In the end-of-project evaluation, concern was raised by a Community Health Facilitator in the OKhahlamba Municipality that, with the extension of the responsibilities and number of the Community Health Workers in the district, the Community Health Facilitators do not have time to reflect on the meaning of the data nor are they receiving any feedback on it. She also expressed the feeling that the other Community Health Facilitators were not interested in analysing and discussing data received by the Community Health Workers.

The Community Health Workers in EMtsheni and ENambithini Municipalities have recently been trained and appointed. The training did not include data collection or the use of information for decision-making and learning. This means that one part of the district does not collect routine data on the households that they visit and, the other part of the district where they do, there is the danger that the process where the data they collected and used for reflection, will stop due to increased workload.

5.3 Social traditions

There are obviously differences in what is described here in terms of individuals and households in the UThukela District, as families interpret and practice traditions non-uniformly. However, the general principles apply to the area, and affected the way in which the IS was designed. An understanding of these traditions and customs helped with the interpretations of the data collected, as well as with the creation of more culturally acceptable output from the design process.

5.3.1 Social organisation

Within the UThukela District 'family' is considered as more extensive than in many western or 'nuclear' contexts. 'Family' forms the basis of Zulu traditional life, which is centred on the *umuzi* (extended homestead). Traditionally the *umuzi* consisted of the headman, with his wives and children, his younger brothers with their wives and families, and, in many cases, married sons as well. With the effects of forced migrations and urbanisation, the *umuzi* has become smaller, often including only one man, his wife (or wives) and children. Strict etiquette and social discipline was applied in a traditional Zulu *umuzi* and to a very large extent is still present in contemporary Zulu homes in rural areas [Magubane, 1998, p. 43]. Children have a close relationship with their grandmothers (maternal and paternal), though the paternal grandmother usually lives in the same kraal as the grandchild. She has considerable authority over the child [Jensen-Krige, 1965, p. 27] and can have quite a powerful decision-making influence at household level.

However, women in general, tend to be dependent on men for income and have very little access to an independent means of livelihood. Household responsibilities also make women subject to 'time poverty', that is, it is not uncommon for most women in this rural area to work ten hours a day, making it a hardship to travel to seek health-care for themselves or their children. Much of each day involves several hours of strenuous manual labour, hauling water and firewood, and performing agricultural work. Women, including mothers, grandmothers and older 'girl children', are predominantly responsible for childcare [TDCSP, 2004].

One source of social, and even political engagement, has historically been the women's prayer unions.

..women's prayer unions provided a key arena in which black women,

excluded from politics and formal organisations to a far greater extent than men, could develop the self-confidence to challenge social relations oppressing them both as black and as women. .. They also served as potent vehicles for the growth of an ethos of collective self-help and solidarity amongst African women. [Bradford, 1987, p. 302]

There are also a large number of other community organisations within the rural and urban communities, such as youth groups, churches and/or church-affiliated groups, women's groups, burial societies and stokvel groups (savings groups), as well as various NGO's. In the 1999 KPC survey [Bergville District Child Survival Project, 1999b], mothers were asked which organisations they belonged to. The responses were:

Church	73.3%
Savings clubs	14%
Burial Society	20%
Women's Group	16.7%
Health committee	6.7%
Development committee	6%

5.3.2 Political structures

Within rural KwaZulu-Natal there is a well-established political organisation. At the base are the households (*imizi*), under the control of the head of the household (traditionally this would have been a man, but with migration this is now often effectively a woman). The head of the household is responsible for the order and running of the household. The head of the household is responsible to the *induna* (the head of the area (*isigodi*)). The *induna* is responsible for all law and order in his *isigodi* and settles disputes which the household head cannot settle or which are too large or important for the head of household to handle. The *isigodi* fall under a larger region (*isifunda*), which is, in turn, overseen by an important district head or hereditary chief (*inkosi*), who is directly responsible to the king. The traditional leader is regarded as a father figure - the source of their wealth and well-being, the spiritual symbol of their tribe, and the man who determines the fate of his people. Much of this structure has survived, largely unchanged, to this day, though some traditional practices are in conflict with the constitution, such as the allocation

of communal land to men only. The allocation of land to women has, therefore, become increasingly common [Magubane, 1998, p. 60].

5.3.3 Communication

Traditionally, decisions that affect the community at large are taken collectively. Community meetings (*imbizo's*) are called and the case for and against the issue are made. Through traditional structures, community members can air their opinions and concerns. This is in keeping with the spirit of *ubuntu* or collective personhood and collective morality [Mbigi, 1997, p. 2] which is a fundamental concept in most African societies. Principles of continuous consultation and consensus, the use of ceremonies to express meaning and the need for spiritual and individual reflection are all principles on which the concept of *ubuntu* is based.

The Zulu language is rich and expressive. Music, song and dance have, traditionally, played an important part in Zulu life on an individual and community level and forms an integral part of daily life. Dance has always been important in maintaining rituals, ceremonial events and bonding during times of stress, joy and change [Magubane, 1998, p. 62]. Each dance formation or movement symbolises an event or happening within the community.

Culturally, children should show respect to adults and should not confront or question adults directly. However, through the family structures (relatives mainly on the fathers' side) [Jensen-Krige, 1965], the concerns of the child can be raised through song and dance. Also in beadwork, for example, every colour has a different meaning, and a Zulu women can weave a message of love, grief, jealousy, poverty or uncertainty into her patterned creation.

One interesting aspect of Zulu tradition is the socially acceptable ways in which women can express themselves. Gunner describes how women, whether royalty or not, could, through praise poems and in the poems they composed for their children, express discomfort and dangers within their household:

Praises . . . give some indication of the way in which women, attached to the royal house through blood or marriage, had access to a genre that allowed for self-expression, self-defence, and self-validation within a wider set of cultural practices that did not encourage such 'writings of the self' on the part of women. Rather, women's personal, private selves were largely silenced, subsumed within the genealogies of male

lines in which women played their part as bearers of children but not markers of lineages. Nevertheless, through the *izangelo* (praises for infants) . . . which were usually poetic, confessional statements about the mother's life as well as comments on domestic politics, and also through *izibongo* (praises of the self), women, whether royal or not, had access to a coded art form that allowed them some means of self-affirmation and self remembrance. [Gunner, 1999, p. 203]

5.3.4 Health and child-care

Traditional medicines still play an important role in the maintenance of the health of an individual. Different types of traditional medical practitioners exist. The herbalist (*inyanga yokwelapha*) administers medicines from plants and animals. The diviner (*inyanga yokubhula*) divines the cause of complaints by using bones, shells, seeds and other artefacts. There are two categories of diviners - the *isangoma* who can make contact with the ancestral spirits and prescribe medicine accordingly and the *isanusi* who divines sorcerers and other evil-doers. Traditionally, *inyanga* and *isangoma* occupy a high status in the community [Magubane, 1998, p. 61].

Health is viewed holistically, not simply as the lack of physical illness. This is easy to explain if the manner in which Zulu people, and many others, understand human beings, is acknowledged.

According to Zulu beliefs, human beings have a body (*umzimba*) and a spirit or soul (*idlozi*). In addition, there is the *inhliziyo* (heart or feeling), the *ingqondo* (brain, mind, understanding) and the *isithunzi* (shadow, personality). The Zulu believe that the *isithunzi* becomes the ancestral spirit after death, but only after the *ukubuyisa* ceremony has been performed, during which the spirit is 'brought back home'. [Magubane, 1998, p. 62]

Thus, health is viewed in terms of how all these aspects of a person interact and function.

It is also important to realise, given this understanding of health and the social organisation of the family, that the care-giver of a child is not an individual but a network "evolving from the socio-cultural structures, norms, values and belief systems" [Sadomba, 2001, p. 5]. Child care is a complex issue within the family and

community, with roles, responsibilities and authority varying, shared, contested and negotiated. If the health-seeking or care-decision involves any financial decisions, the head of the household, which is usually a man, will need to be consulted in order to make the final decision. This process often causes a delay in a child attending a clinic as money for transport and alternative child-care for the siblings would need to be found.

Within a health care setting, for instance, even though the mother is the one who takes the child to a health facility, she cannot implement some of the advice without consulting other members of the family. Eventual compliance depends on the grandmother or father, who may overrule her. [Sadomba, 2001, p .2]

Though this is in reference to Zimbabwe, the social arrangements in relation to the care of child, are equally applicable in the rural area of the UThukela District. Grandmothers, traditional and spiritual healers are often the first persons to be consulted in times of illness, and many locally available remedies and treatments are used and practised [Gibson et al., 2000].

5.4 Conclusion - implications of structuration process in IS design

There were a number of ways in which viewing the context through the lens of Structuration Theory helped in the design and implementation of the CBIS. Firstly, there was the sensitising function it served. Secondly, the implications of examining the context in terms of the modalities also highlighted some opportunities and challenges which would need to be embraced by a revision of the IS to include a community component.

5.4.1 Sensitising function

An understanding of the difficult process of local government transformation and the restructuring of the health sector, along with an understanding of the community approach to decision-making, enabled a more sensitive approach to be adopted. This understanding was enabled through the Projects involvement in the community

for several years and its mission values. Thus there was a good trusting relationship established between government and community people. Furthermore, using the collective decision-making approach of the community, the project on child health was firstly discussed at community meetings. The need to develop a CBIS, which would allow community members monitor their children's health status, was a recommendation from a monitoring and evaluation workshop, where community members, district health staff, researchers, UNICEF and TDCSP staff were present.

5.4.2 Opportunities and challenges raised

Some of the opportunities which arose from an understanding of the context were:

- The appointment of new local government role-players provided an opportune time in which to introduce change, as changes in IS could take place within the changes planned in the existing work processes. These new role players would also be crucial in terms of resource allocation in the future (facility). The newly-formed local government structures established clear communication channels with higher levels of local government and this could be an opportunity for the IS to link with these communication channels.
- There was the need for a paradigm shift in line with the restructuring of the health services. This shift was from the older more curative health service approach to the newer client and service-focused approach of PHC. With the newly-established local Clinic and Community Health Committees, this offered an opportunity for new people to come into the health sector with a new vision and who were also willing to be involved in the IS design process that would support their work. The client-focussed approach and recognition of community participation meant that different meanings and ideologies regarding health care were recognised as valid within this paradigm shift. As such the norms had changed since 1994.
- The appointment of Community Health Workers meant that the link between the households and the formal health sector was formally recognised. This established, or had at least the potential to, a good communication loop. The more holistic view of child care as a 'family' decision could be facilitated through family discussions on child care by the Community Health Workers and facilitate the sharing of knowledge (and thus changing interpretative schemes). This could be done through household visits and the Community

Health Workers could then play an important mediator in the integration of community data with data collected from other sources.

- When any group came together there was a great deal of singing, dancing and praying. People clearly enjoyed and were comfortable communicating with one another in this way. Thus this mode of interpretative schemes could be used also in the IS design process.

Some of the challenges that needed to be addressed were:

- The position of the DIO was unfilled. The supervisor of the DIO was requested, and agreed, to take part in the research and as such, higher level facilities were engaged in the research process in an attempt to gain greater sustainability of the system. Luckily the District Manager, though in an acting position for several years, was committed to the long term management of the District and was highly motivated.
- Using a participatory approach in a situation where staff were overworked at the clinics (due to shortages and illness) and a situation where women were under severe time constraint meant that a flexible approach would need to be adopted. The process would need to avoid increasing the workload of those with less resources (facilities).
- The strong social hierarchy, and thus facilities, would need to be used effectively to enable the participation of women and children and care would need to be taken that these power structures would not impede the participatory nature of the IS design process. This could be facilitated through the use of the traditional groups or gatherings and traditional forms of communication (song, dance and praise poems).
- Implementing a paradigm shift to PHC and a client-centred approach was difficult, even if it was legislated. It involved changing the norms of both the health service staff and the clients themselves. The history of non participation in terms of delivery of services, and only certain areas within the district having established functional community health forums, meant that it was not an easy transition. Furthermore, the staff at the centres had a bio-medical focus on health (management of disease/illness) and were trained in this way. Combining the different ideologies and meanings associated with child health would need to be tackled strategically as the meanings and interpretations of child health would be fundamental in establishing the boundaries of the

subsequently implemented child-health community-based IS.

Thus by using the modalities of ST the context can be analysed and the opportunities and challenges for the design process highlighted. This can be done for various time periods to assist with the understanding of the changes which take place in the social processes over time. Examples of such a framework are given in Tables 5.2 and 5.3 for the period before 1994 and the period after 1994.

Time period	Modality	Relevance of context to IS design
Pre 1994	Interpretative schemes	<p><i>Opportunities:</i></p> <ul style="list-style-type: none"> * Traditional knowledge on health seeking behaviour and child care. * Elders and traditional healers as custodians of that knowledge. * Expression through song and dance. <p><i>Challenges:</i></p> <ul style="list-style-type: none"> * Information shared limited to directives and government circulars. <p>Information collected used for control.</p>
	Facility	<p><i>Opportunities:</i></p> <ul style="list-style-type: none"> * Strong traditional powers on allocation of land and decision making at local level. * Community meetings for decision-making. <p><i>Challenges:</i></p> <ul style="list-style-type: none"> * Decisions on the allocation of resources based on national level decisions and policies.
	Norms	<p><i>Opportunities:</i></p> <ul style="list-style-type: none"> * Strong reliance on socially accepted child rearing practices and repercussions of unacceptable behaviour. * Respect for community elders <p><i>Challenges:</i></p> <p>8 HIS was legitimised by the norm of a 'top-down' authoritarian approach of the government.</p>

Table 5.2: Context pre-1994

Structuration theory contributed substantially to understanding the context and the process of changes in the context in which the community lived. Having being involved with the TDCSP for several years I found this framework an especially useful tool as I was so embedded in the context and possibly blind to many of the elements which the use of this framework highlighted. This framework can assist in providing other researchers with a useful lens for viewing their context. As

Time period	Modality	Relevance of context to IS design
Post 1994	Interpretative schemes	<p><i>Opportunities:</i></p> <ul style="list-style-type: none"> * Household orientation of community health workers in line with holistic view of health and health care as a collective decision. Could also act as mediator. * DHIS established by the Project and taken over by district dept. of health, but little evidence of data being utilised for action. * Expression through song and dance. <p><i>Challenges:</i></p> <ul style="list-style-type: none"> * Many sources of data and different information systems in the different sectors.
	Facility	<p><i>Opportunities:</i></p> <ul style="list-style-type: none"> * The constitution enshrined community participation in the delivery of health services. * Local government management decision-making bodies established. * Community meetings for decision-making. * Employment of community health workers in the complete district. <p><i>Challenges:</i></p> <ul style="list-style-type: none"> * Traditional chiefs and leaders highly regarded by community they served, but position being eroded under new restructuring of local government. * Limited human resource capacity of local government staff in terms of delivery of services and community forums only established in some areas. * Positions at district level not made permanent or unfilled. * Women still with little decision-making capacity, though legal position improved.
	Norms	<p><i>Opportunities:</i></p> <ul style="list-style-type: none"> * DHIS established in consultation with some clinic and district department of health staff. * Project had strategies of community participation and capacity development in all programmes. * Client-serviced approach to the delivery of health services <p><i>Challenges:</i></p> <ul style="list-style-type: none"> * Health delivery staff had a bio-medical (curing of disease/illness) focus on health and were trained in this way, whereas community members held a more holistic view of health.

Table 5.3: Context post-1994

Structuration Theory is a meta-theory other theories such as Actor-Network Theory or Activity Theory [Korpela et al., 2004] can be used to explore the detail of specific work and social processes within the context.

Part III

Process and output

Chapter 6

The Process of developing a Community-Based Information System

This chapter focuses on the initial steps taken in the process of developing the child-health CBIS. A participatory action research framework was adopted, as described in Chapter 4, Section 4.3.2. In this chapter, the various components of that framework are described. The research questions concerning the process of design that are specifically addressed in this chapter are:

- **What is the vision of the community for the health of their children?**
- **How does the existing DHIS assist with the assessment of the situation of children's health and in identifying action to be taken with respect to the vision of the community?**
- **How can information flows be designed that facilitate the integration of the CBIS with the formal health facility IS?**

6.1 Introduction

Whereas the previous chapter painted the background and context in which the research was conducted, this chapter focuses on the process which was followed in the designing of the child-health CBIS. This chapter focuses on the answers to the first three research questions as outlined in Chapter 3 (Section 3.6):

- What is the vision of the community for the health of their children?
- How does the existing DHIS assist with the assessment of the situation of children and in identifying action to be taken with respect to the vision of the community?
- How can information flows be designed that facilitate the integration of the CBIS with the formal health facility IS?

In the first section of this chapter I return to the participatory action framework as set out in Chapter 4 (Section 4.3.2) and go through each of the stages of that framework in the process of designing the IS. After this, I return to specifically address the above research questions.

6.2 Overview of the design process

Chapter 4 (Section 4.3.2) outlined the participatory action research framework which was adopted in the process of conducting this research. Each stage of the participatory action research model is discussed in greater detail in this section.

- *Client-system infrastructure*: The main activity in this stage was reaching agreement between the insiders and the outsiders in terms of the objectives of the research, the roles and responsibilities, the resources needed and the principles of operation.
- *Diagnosing*: This stage involved planning the research process. This commenced with vision building and then conducting a participatory situational assessment and analysis.
- *Action Planning*: Once agreement was reached on the objectives and a greater understanding of the context was developed plans for conducting the research were made.

- *Action taking*: After the research was conducted the fieldwork was analysed and an action plan was implemented.
- *Participatory Evaluating*: As a result of the delays in the implementation of the IS, the evaluation of the system took place earlier than would be optimal, a mere six months after the initial revisions had been implemented. This meant that the evaluation focused on the process of the CBIS, rather than the impact on child health.
- *Specifying learning and revising action*: Lastly, I briefly introduce some of the experiences of sharing the lessons from the process.

6.2.1 Client-System Infrastructure

A participatory situational analysis was conducted in the initial stages of the community child-health intervention of TDCSP to see what information was available on the situation of children in two pilot communities (*isigodi's*) - Loskop and Oliviershoek [Gibson et al., 1999]. Gaps in the information were identified and further research was conducted to fill those gaps [Gibson et al., 2000]. From the participatory situational analysis and assessment the main people responsible for child-health (the duty bearers) and other key people in the community (the role players) were identified¹.

Participatory techniques, such as PLA methods, were used to assist in the gathering, interpreting and analysis of the information. An example of the identification of the main role players and duty bearers is illustrated in the photograph in Figure 6.1. The photograph shows the child at the centre of the picture and the rest of the duty bearers and role players in circles of differing distances from the child. The closer the circle is to the child the more important is that role player or duty bearer. If action needed to be taken to improve the care of the children of the community it was felt that these people would need to be involved in the design of an IS. The following groups of people, therefore, participated in the research: Community Health Workers, Clinic Health Committees, traditional leaders, councillors, social workers,

¹A duty bearer is a person who is legally obliged to fulfil certain rights, a claim-holder or rights-holder is the subject who is entitled to the right and a role player is a person who is engaged, whether obliged or not, in the process of realising that right.



Figure 6.1: Identification of duty bearers and role players

early childhood practitioners, mothers (including teenagers), fathers, grandmothers and TDCSP staff.

It was necessary to establish a working group to conduct the research. Participants for the working team were selected based on the positions they held within the district, the networks they were currently part of, the skills and expertise they possessed, as well as their willingness to participate. As a result, the following categories of people (and the networks they were part of) agreed to attend the meeting and be involved in developing the CBIS:

- PHC Coordinators - contact with the Department of Health and local government;
- Facility Information Officer - contact with Department of Health and the facility HIS;
- Community Health Facilitator - contact with community groups and have organised many PLA sessions within the community already;
- Community Field facilitators - contact with the Clinic and Community Health

Committees, the Health Forums, youth groups and other grassroots organisations, and;

- TDCSP staff - contact with the child-health interventions, National and Provincial Department of Health, World Vision and UNICEF.

The roles and responsibilities of all parties were not only agreed to and documented for clarification purposes, but also to avoid confusion or misunderstanding arising at a later date. Though many participants had experience in monitoring and evaluation and had been involved, although to a lesser extent, with the community component of IMCI and child-health interventions, brief presentations were made to all team members on what had been done in the district around IMCI, the existing monitoring and IS and capacity development. These presentations were felt to be necessary so that a common starting point was established.

To reconfirm the identify of the duty bearers and role players one of the tasks of the research team meeting was to ask research participants which of the key role players should be included in developing the monitoring and evaluation system. This reconfirmation was important to do as, with changes in the socio-economic, environmental and political conditions role players and duty bearers would change over time². The duty bearers and role players identified at this meeting were the same as those identified earlier in the participatory situational analysis. It was noted after the initial meeting that children and youth had not been explicitly included in the groups to be included in defining and measuring vulnerability. This was raised in a subsequent meeting and the same participants felt that there was the need to include youth and children separately and also to include teenage mothers as a separate group to the group on mothers, fathers and care-givers.

6.2.2 Diagnosing

Vision Building

When the Child Survival Project commenced the community child-health intervention, agreement on the vision and objectives of the intervention had been agreed to through PLA sessions with community participants in Loskop and Okhombe, different wards in different sub-districts. The vision was: *to achieve optimal health,*

²One example of a major change in duty bearers was the move towards local government delivery of health services. Previously the HIS did not include these duty bearers.

growth, development and well-being of children within the family and community in the UThukela Health District. However, co-determining visions and objectives based on that vision is a process that needs to be done more than once, as the oKhahlamba experience illustrated.

In a monitoring and evaluation workshop held in Bergville in February 2000, it became evident that very few women who attended that workshop could understand the 'co-determined' objectives. The objectives were translated, both in terms of the terminology used and also to simple English and then to isiZulu. It became clear that, even though the objectives had initially been agreed to in another community meeting, they were not representative of the views of this particular group of workshop participants.

Two important lessons were learnt in the UThukela District, when the objectives of the CBIS research were identified with different groups of people at different stages of the research. These were:

- Developing 'co-determined' objectives depends on the particular group of participants. Even though the objectives had initially been agreed to in another community meeting, they were not representative of the views of this particular group from the same community.
- Contexts change over time and, therefore, so do priorities. In line with this changing context it was necessary to maintain some flexibility in terms of the objectives.

Participatory Situational Assessment

The TDCSP conducted a participatory situational analysis and assessment at the commencement of the community child-health intervention in 1999. This involved a demographic overview of the OKhahlamba-EMtshezi District, a review of the health services in the pilot area and a summary of the health information gained from the facility-based HIS and the Community Health Workers in the then OKhahlamba Sub-District. It further explored and described the community infrastructure in the district and reported on the results of FGD's and PLA sessions on child-health and care-seeking practices. From the research, a glossary of local terms for childhood illnesses was developed. Gaps in the information about child health were investigated at a later stage, through FGD's, critical incidence analysis and further PLA sessions.

Based on the situational assessment, it was agreed that the first step in designing an IS to support community members to monitor the situation of their children, required community members to visualise what they wanted to achieve for their children. Community meetings were called and PLA sessions were conducted to reach a common agreement on the objectives of a child-health intervention. Once the objectives in the February 2000 monitoring and evaluating workshop held in Bergville were agreed upon, participants were asked to arrange themselves into groups and to discuss the following question: *If we are achieving these objectives what can we SEE, HEAR and how can we MEASURE what is happening?* Decisions made depend on the informational base and indicators selected [Sen, 1999].

Interestingly, some of the indicators that emerged from this exercise were similar to indicators already existing in the formal DHIS, such as the percentage of children immunised and breastfed. Other indicators were not so clearly measurable, such as abuse at the household level. Community members and other participants said that it could be measured through being able to 'See and Hear' less abuse. It was felt that more work would need to be done to explore the 'See and Hear' aspects of a monitoring system.

In a subsequent workshop to further develop the system, there was discussion on whether a participatory CBIS was required. It was noted in the discussion that very few of the current indicators are community identified and that there was the need for community members to be involved in determining them. This was also important in developing and strengthening the partnership between health services and the people they served. This would facilitate action being taken once the data was collected. Part of the discussion in these initial meetings was also around determining a local term for indicators or 'signpost'. There was some debate over using *izimpawu* (signs) or *izinkomba* (pointers). The research team agreed on the term *izinkomba* as it was felt to be more specific. Other isiZulu terms used in the conducting of the research were: *impilo ephelele* (well-being); *ebucayini* (at-risk), and *ukulinganisa* or *ukukala* (measure).

There was agreement, based on the outcome of these meetings, that local measures of child-health and wellness were needed, that some HIS data was useful but was not being sent to the relevant people and that communities wanted to be involved in the process of changing the HIS.

6.2.3 Action planning

As the agreed vision was around the attainment of 'holistic health and well-being' for their children, one of the initial challenges of the participatory process was to understand what meaning was attached to a child being in a 'state of well-being' by the various groups. In deciding on how to gain greater understanding of the different perspectives on the vision, one of the first issues addressed was the terms, questions and methods to be used. Through participatory exercises, the research team initially addressed the question of whether to use the term 'vulnerability', 'at-risk' or 'well-being'. They discussed the question, in two groups, and wrote their answers on pieces of paper. One member of the group then placed their pieces of paper on the wall under separate columns for 'vulnerable', 'at-risk' and 'well-being'. The value of the exercise was in the ensuing discussion, where agreement was reached on the terms that should be used in the research.

In the discussion, various definitions of 'vulnerability' were aired. These included "*context to watch so child does not become at risk*" and "*healthy child in an unhealthy environment*". Definitions of child 'at-risk' included "*child already in-risk*" and "*unhealthy child in unhealthy or unsafe environment*". Other participants felt that the terms meant the same thing. The groupwork on defining 'well-being' illustrated a more holistic view of the child that went beyond 'health' issues and covered the broader environment. It included networks, support and love. This is in keeping with the Zulu understanding of a person and their holistic approach to health which was described in Chapter 5, Section 5.3.4. The discussion on 'at-risk' focused more at the household level. After some discussion on the terms to be used in the research it was agreed to look at both 'well-being' and 'at-risk', as both situations would require action. One important element which arose out of these discussions in the UThukela District was the need to move beyond the measurement of child-health status in terms of the physical being, to a more holistic approach and to include the context in which the child is living.

Generic research instruments were developed by the research team in a subsequent meeting. Participants were grouped according to the type of data collection method to be used, for example theatre, FGD's and interviews. They designed the research instruments to be used for that data collection method. Some guiding principles on the development of the instruments were discussed and agreed upon. These were:

- to describe what participants understand by 'well-being' and 'at-risk' for a child;
- to outline what factors/practices contribute to the 'well-being' and 'at-risk' for a child;
- to prioritise the factors/practices outlined;
- to explore which households in the district are viewed as having children 'at-risk' and in 'well-being' and why (this can be compared to the generic factors/practices already outlined);
- to explore how 'well-being' and 'at-risk' can be measured (determining *izinkomba*);
- to determine what action can be taken and by whom based on these measures, and;
- the facilitator, to observe the degree and level of participation of the various participant groupings, e.g. men/women, young/old, status or level.

Attention to the discussions that took place in defining the terms and in identifying the *izinkomba* was also taken as being very important. At the end of the meeting each group refined the instrument for their particular context, that is those people working with the youth would unlikely use the exact same instrument as those people working with the councillors.

6.2.4 Action taking

Participatory methods were employed in order to understand the context (powers, traditions and customs, socio-economic conditions) in which community members live. The results from a DHIS review, held in November 2001, along with the results of the participatory situation analysis (June 2000), were also drawn upon for the analysis. This has been explained above (Section 6.2.2).

Discussions were facilitated from people who were familiar with the geographical area and who also had an understanding of the local norms and values, such as the Community Health Workers, Community Field Facilitators and orphan group 'mothers'. In the initial stages because of these differentials in status and roles within the community, groups comprising, for example, mothers, children, councillors and facility staff, met separately to discuss what they wanted for children. That is, a number of 'sub-spheres' were formed, rather than one large 'public sphere'. These meetings were held in the local language and near the homes of the individuals. The Community Health Worker played the essential mediation role between

the service providers and the community members who are the users, or potential users, of the service. At a later stage, representatives from the various groups met jointly to share the findings from the research and to discuss the way forward.

Through the various FGD's and interviews, definitions for a child 'at-risk' and 'well-being' and also the conditions that contributed to these conditions were discussed. The main issues raised for a child 'at-risk' were:

- not having parents present (either dead, migrant workers or just not physically present to look after child), and;
- not being physically healthy (suffering from recurrent and common illnesses, sores, kwashiorkor).

The participants also identified that a child 'at-risk' was: not growing well; abused (physically, sexually and emotionally - *'being shouted at'*, rights being violated); living in a household with poor hygiene practices (the most important was using dirty water and not washing the child), and did not play with other children. Some of the other factors that the participants felt were also important are detailed in the Table 6.1 categorised according to the level at which the situation could be observed.

Many of the factors for a child to be viewed as being in a state of 'well-being' were the opposite of those for 'at-risk' (see Table 6.2). Being active and playing, having sufficient nutritious food and breastfed, as well as a conducive household environment were raised the most frequently. As one early childhood practitioner said, *"A child that grows under a family with good communication grows up with a happy face."*

It is interesting to explore the differences between the definitions of 'at-risk' or 'well-being'. Alcohol and drug abuse was viewed as being important in defining a child 'at-risk', but the absence of such abuse was not mentioned when discussing 'well-being'. However, this could be related to the fact that a good household environment with love could be synonymous with a household without alcohol and drug abuse. HIV/AIDS was not specifically mentioned. However, the affects of the disease on the child can be seen through parents not being present, physical health, growth of the child and family health. The causes for children being 'at-risk' are important to understand if the situation for children is to change to one of 'well-being'. It is the context in which a child is placed that should be monitored, as well as the condition the child is in.

Level	Meaning
Child	Physically unhealthy Poor Growth Child abused Unhappy Inactive/playing
Household	Insufficient food and nutrition Unhygienic practices Poor family health Alcohol and drug abuse Poor routine caring practices Poor relationship between children and adults Parents not present No shelter Torn/poor clothing No birth certificate Poor relationship between parents
Community	Far from health facility Lacking safe/potable water Little income/unemployment

Table 6.1: Meaning of 'at-risk'

For the participants in the research, the factors affecting the conditions for 'well-being' and 'at-risk' that were commonly raised were: food and nutrition; love; a good relationship and communication between parents; a good communication and between parents and the child, and care from the parents. One person from a Community Health Committee stressed, that there needs to be a parent present so that we do not *'leave the child to stroll in the road'*. Another mentioned that a 'well-being' house was *'one with warm hands'*. These factors are not isolated, but are interwoven in a socially, politically and culturally complex situation.

It is important to monitor the context in which a child is living (the process towards 'well-being' or 'risk') as well as the state of 'well-being' and 'at-risk' (end product). If we focus on the end product and it is a negative outcome, it is too late in many cases to act to improve the situation of the child. Table 6.3 lists the conditions participants felt affected the process of 'well-being' or 'at-risk'.

As agreed in one of the initial meetings, a local term for indicators or 'signpost' - *izinkomba* (pointers) was used in the research. So we then asked, given their

Level	Meaning
Child	Active and plays Good nutrition and breastfeeding Growing well Physically healthy or Absence of Illnesses Developmental milestones attained (including psychosocial development) Needs met Happiness Rights met
Household	Good relationship and communication with parents Good household environment Love Parents present Appropriate care-seeking and care of the child Income/Access to material goods Good hygienic practices Birth certificate House in good condition
Community	Access to education Potable water

Table 6.2: Meaning of 'well-being'

definitions of 'at-risk' and 'well-being', how would you measure it? What *izinkomba* would you use to tell whether a child was on the path to 'well-being' or not? At this stage the discussions explored broad areas of measurement rather than developing precise formulations of indicators. This was because community members felt that they were not looking for a value to be placed on childhood vulnerability or risk, but rather there was the need to track changes in this status, to know when action needed to be taken when a child was falling into risk or danger.

From the predominant focus on quantitative indicators in IS design, reflecting a positive technical tradition in the medical field, there is still an emphasis on absolutes and on quantification within HIS. Increasingly there are a number of criticisms of this approach [Walsham, 1993] [Berg and Goorman, 1999] which outline the need for a more interpretivist and situated approach to IS design. Robert Chambers is one such critic from the social developmental field of the emphasis on quantification. Chambers criticises the traditional emphasis on quantities and income measurements and the accompanying claims that they are objective and the

Level	Conditions for 'well-being'	Conditions for 'at-risk'
Child	Active/playful Sufficient food and nutrition Adequate clothing Happiness Physically healthy Growing well	Inactive/not playing Poor/Inadequate food and nutrition Not immunised Unhappy Physically unhealthy Abused child Lack of birth certificate/identification document Poor clothing
Household	Good housing Good family practices Hygienic practices Caretaker and/or parent present Parents relationship good Good communication with parents Attends clinics Love	Large family size Poor communication between parents Poor care of child Parents not present Unhygienic practices Alcohol/drug abuse Poor relationships within family Poor housing Lack of love
Community	Access to education Open spaces to play Income/employment	No access to education No income/unemployed

Table 6.3: Conditions for 'well-being' and 'at-risk'

only possible measure of development. He argues that

Quantification and statistics can mislead, distract, be wasteful, simply not make sense, or conflict with common values. . . . What is measured may also not be what matters. Real per capita GDP (Gross Domestic Product) is still widely used as an indicator of how well a country is doing : yet much ill-being contributes to GDP. In the accounts, much of the bad life is counted as positive. . . .

Nor can figures that are used and quoted be considered objective. There are always problems of measurement, representativeness and meaning. Though well known, these are rarely mentioned when results are reported and cited. . . . Figures so selected are then accepted, repeated, cumulatively misquoted and used, consciously or unconsciously, to reinforce predisposition and prejudice. [Chambers, 1999, p. 40]

Within these quantities and statistics, power and influence go unquestioned. "In power and influence, counting counts. Quantification brings credibility. But figures and tables can deceive, and numbers construct their own realities. What can be measured and manipulated statistically is then not only seen as real; it comes to be seen as the only or the whole reality." [Chambers, 1999, p. 42] Power and influences are important, not just in deciding what data items to collect, but also in terms of who participates in the design, implementation and day-to-day operation of the system.

Chambers also challenges the pursuit of excessive accuracy of data when approximations are good enough. He notes that "What often matter are judgements of trends and of relative amounts, and insights into causality". He urges people to aim for 'approximate precision' as well as accepting 'optimal ignorance', or knowing only what you need to know. It is a view reconfirmed by Guijt,

When thinking about impact and the accuracy with which impacts need to be known, the adage 'it is better to be approximately right than precisely wrong' can be a useful reminder about what is important - as long as approximations are not distorted and presented as more precise than they in fact are. The accuracy with which impacts need to be known determines what unit of measurement is required, and thus influences the final choice of indicator and method. [Guijt, 1998, p. 20]

However, the health system is complex and one level of the health system needs to be able to 'talk' to another level. IS need to be compatible with higher level systems. Of course the corollary is also true - higher level IS should feed back in appropriate ways into local level IS. Community-based indicators should be selected for collection by the community, but there is need for standardisation of the indicators that are to be sent between the different levels of the administration hierarchy. It is a delicate balance of localisation and standardisation. It was agreed that much of the current data collected was useful for the child-health strategy IMCI, that the Department of Health had adopted. Some of the community selected indicators were the same as some of these indicators. To ensure consistency between the different data sources, standardised definitions of the data items and the indicators would need to be used. It was agreed that the IMCI definitions would be used for the similar community selected *izinkomba* as participants had similar understanding and meaning for these indicators.

The research identified that, while some data for 'at-risk' and 'well-being' is currently collected in the DHIS, this data is not being delivered back to the people responsible for taking action at the household level. Another gap identified was the need to include in the DHIS indicators of the context which shapes the status of children. Examples of such indicators were the percentage of children in the community with good communication between parents, and the percentage of children living in a loving household. This type of data cannot be collected through 'facility based' HIS, but needs to be largely articulated from and collected within the community.

Based on these findings, the process of refining the *izinkomba* took place. From the FGD's, various *izinkomba* for 'well-being' and 'at-risk' were suggested (see Table 6.4) and these were subsequently grouped through group sessions into common areas or themes. Some of the suggested questions that needed to be answered to address these *izinkomba* is given in Table 6.5 at the end of this chapter.

	At-risk	Well-being
Child	Inactive Unhappy Poor physical health Inadequate clothing Alcohol and drug abuse Poor growth Not cared for by parents	Active and plays with others Happiness Good health and appearance Good growth Attaining developmental milestones including psycho-social development
Household	IMCI danger signs present No regular growth monitoring Inadequate food and nutrition Unhygienic practices Poor relationship of parents Poor caring practices Family at risk	Hygienic practices Good communication between parents Good food and nutrition Children cared for Good relationship of parents Regular clinic visits Love Clothing
Community	Poor or no income Poor housing Poor access to safe water Uncaring community	Income or employment Good housing Access to education Open space for playing

Table 6.4: *Izinkomba* ('measures') of 'at-risk' and 'well-being'

Further working sessions with representatives from the District Health Management Team, the Project and community members as well as a discussion with the Community Health Workers were conducted to refine the *izinkomba*. (The recommended list of *izinkomba* was subsequently developed in later meetings and is outlined in Chapter 7, Section 7.1.) Once there was a clear picture of what the community wanted to measure, what was currently available and in what format, a review meeting of community members, with district staff and provincial steering committee members, was held.

It was generally agreed that measures for conditions like communication, relationships, happiness and love should be included. Significant time was spent, as well as a great deal of frustration, struggling with the development of indicators for these conditions. These conditions are crucial aspects of the vision and there was the need to know how to assess whether that vision was being reached or not. Some progress was made in deciding on proxy indicators for the 'care of the child', such as having a birth certificate and having a mother present, but little progress was made in this district level meeting.

A meeting with the Community Health Workers for the UThukela District was called with the tasks to review the Community Health Workers data collection tools, data analysis and information flow. The Community Health Workers also tackled the issue of measuring the conditions of love, communication and other *izinkomba* which the district health and the Project staff had tackled previously. The Community Health Workers and Facilitators felt they could collect data on all of these measures. It is interesting to note that, even though there was difficulty with this task in a previous meeting with district staff (December 2002), the Community Health Facilitators and Community Health Workers did not have difficulty with this task and completed the task very quickly.

Following on from these discussions, the use of a community assessment tool was piloted as an approach to measure these type of *izinkomba*. Participants felt strongly that the assessment should be used as an empowering communication tool, rather than as a means of inspection. This would need to be carefully implemented after a meeting with the Community Health Workers on its use had taken place.

The capacity of the role players and duty bearers to act if they received the necessary information or knowledge was then addressed. Most of the participants felt that action could be taken, given current capacities, and the ongoing support

of the health care system, if they received adequate and timely information. It was agreed that much of the data collected through the DHIS is valid and useful. An important requisite was access to the data, as the data was not flowing to people who could take action. Key role players, according to our analysis, who are not receiving this data are: Community Health Committee's, councillors, social workers, Home-Based Carers, early-childhood practitioners, traditional leaders and parents/care-givers. Some of these role players were very keen to be involved. One Project officer mentioned in an interview that, during their meetings with the Community Health Committees, there were high levels of enthusiasm and commitment to do something about the situation of the children in their communities. She felt that the Community Health Committees would be central in the information flow, as the Community Health Committees also attend the *imbizo's* (community meetings) and are given time on the agenda. Therefore, they would be a good link with the traditional structures as well as with the community members who attend the meetings. The Community Health Committees are also recognised by the councillors and the information the councillors receive from the Community Health Committees is trusted and respected.

Based on these discussions changes in the information flow were recommended, as well as changes in the format of the routine district data. It was recommended that the District Information Officer summarise the data collected on a quarterly basis and send a summary sheet back to the newly formed Community Health Committees. This summary sheet will be 'acted' out, through poetry, song and dance in the quarterly village health days.

However, we need also to bear in mind that at times it may be personally dangerous to be involved in the information flow. From the interviews and FGD's, the fear of being bewitched by the neighbour if you indicated that the house was 'at-risk' was raised. Furthermore, a social worker had previously been told she would be shot if she intervened in a child abuse case. One Project member suggested the possibility of exploring a confidential IS, but warned against this becoming a gossiping channel. As indicated in Chapter 2 an important objective of Critical Social Theory is to initiate a process of self-reflection among human actors and to create awareness of these constraining factors facing them so that people can make decisions on how to address them. Only participants in the community can decide on the action to take. Therefore, the decision on the format of the CBIS was left up

to the community members. They were most knowledgeable of the context. Due to the confidence in the Community Health Worker it was felt, by the community participants, that she/he should be the mediator between the households and other levels of the IS. No unique identifiable data would go beyond the Community Health Worker.

Throughout the interviews, discussions and meetings, networking was raised as being of importance. Facility staff at one clinic stated:

There is no visible networking or working relationship between the health facility staff and the social workers. Some risk situations of the children are due to social related problems, where other children need to be referred to social workers. No follow up is done or there is no known destination in the efforts taken before the problem can be declared resolved.

They recommended after this discussion that they would invite the social worker to attend their next meeting. An IS at a local level between these actors would enable this network to be established.

In summary, four main changes were made to the HIS in OKhahlamba Municipality. The first was the determination and inclusion of the indicators the community wanted into the IS. The second major change was the adaptation of the existing Community Health Worker data collection forms to include these indicators. Thirdly to stimulate reflection and use of the community-based data, the various forums for analysis were strengthened. The last change was in the information flows. Households receive feedback immediately from the Community Health Worker during her visits, communities receive the information at the village health days, and health facility staff receive the information through the reports from the District Information Officer. These changes are described in the next chapter (Chapter 7).

6.2.5 Participatory evaluation

The evaluation of the Project, which included an evaluation of all the interventions and hence also the DHIS, was conducted in November 2003. Identifiable benefits to date have largely been process-oriented: in other words, improving the processes

by which the HIS operates rather than the impact the IS had on child-health. The main benefits of CBIS were identified as:

- reducing the number of data collection tools from 5 forms to 2: an observation form for each household visit and a monthly summary form;
- training of 75 Community Health Workers, and involvement of those workers in the design process;
- development of a culture of needing information with the Community Health Workers, especially around growth monitoring and promotion, and;
- reducing the amount of time required for data collation in monthly Community Health Worker meetings from 3 hours to 1 hour.

More broadly, the CBIS research has helped to emphasise the importance of information at community level within a DHIS, making it clearer where information should flow based on who can take action, and highlighting the importance of feedback of information to the community-level partners in child-health.

Given that the CBIS has only recently been implemented it was really too early to judge its impact on broader health system outputs, such as child-health. However, the overall child health intervention, within which the CBIS resides, has been shown to have had a positive impact on child-health as measured through improved immunisation rates, improved knowledge and care-seeking behaviour, and improved breastfeeding rates.

A number of enablers or critical success factors were also identified:

- *Prior foundation.* One reason behind the success of the CBIS was the foundation of pre-existing work on health systems. The existing DHIS had been developed in the first phase of activities of the Project and provided a platform from which that IS could be expanded to include the community. During earlier work, the TDCSP had also established a partnership with the community and the Department of Health that was an important foundation for the CBIS.
- *Being part of a larger whole.* Having the CBIS as part of a larger community and district health intervention meant that easy access to the community and a forum for allowing feedback of information to the community for reflection and evaluation were already in place. Further, the outputs of the research could easily be fed into planned interventions, such as training on

child-health for the Community Health Committees. Making HIS interventions an integrated part of a larger child-health intervention is, thus, one key to success.

The constraints or challenges identified included:

- *Shifting responsibilities.* The Community Health Workers moved from being employed by TDCSP to being employed by the government's Department of Health, though still remaining accountable to the Community Health Committees. With this change, the scope of the work the Community Health Workers were doing widened considerably - from a specific focus on households with 'at-risk' children of under five years, to a very broad community development focus. This shifted the amount of time that they spent with the households with children and decreased motivation for data collection on children.
- *Vacant positions.* The position of District Information Officer was vacant for the duration of the CBIS participatory development. It was, therefore, difficult to embed the culture of the CBIS into the DHIS during this period (though since the appointment of an officer the CBIS has been fully endorsed and there has been agreement to expand the process to the rest of the district).
- *Non-overlapping data sets.* The areas within which the Community Health Workers operate are not coterminous with the catchment areas used by the Department of Health for each health facility. This has made it difficult to include community-based information at the lower levels.

Based on the field work, the CBIS was implemented in the municipality in June 2003, and agreement was reached at district level to expand the system to the rest of the district. However as the TDCSP leader commented in the evaluation of the Project, *"This process has shifted thinking within the Project from the idea of the monitoring of community interventions to the empowering approach of communities monitoring themselves and the status of their children. . . . The work shows potential but is still in its infancy"* .

6.2.6 Specifying learning and revising action

Throughout the process, reports have been written and circulated amongst the researchers, TDCSP staff, provincial IMCI coordinators and National and District

Department of Health. A number of presentations were also given at national and provincial level to representatives of Maternal and Child Health Directorates, IMCI coordinators, representatives from the University of the Western Cape and UNICEF staff. The newly appointed KwaZulu-Natal Community Health Worker unit was also informed of the process through the TDCSP, but the position was subsequently vacated and was not filled at the time of writing.

Community structures have been included in the information flow and these structures are linked with the local government structures. It is the local government who are responsible for the delivery of the basic social services. As such it is important that they are included in the information flows and decision making structures.

The information flows identified will, potentially, lead to improved networking and communication. The system will be continuously refined in the initial stages of implementation. Other specific lessons learned are dealt with in the subsequent chapters. Namely, the rethinking of participation, understanding communication, reviewing the output and generalisations.

6.3 Conclusion

At this point it is appropriate to return to the three research questions posed at the beginning of this chapter.

6.3.1 What is the vision of the community for the health of their children?

After a number of PLA sessions, meetings and FGD's the vision for the UThukela District was given as: *to achieve optimal health, growth, development and well-being of children within the family and community in the UThukela Health District.* It was more important, however, to discover the underlying different meanings of community members in terms of that vision. The different emphasis on 'at-risk' and 'well-being' were all taken into account when designing the new data collection tools, information flows and other artefacts of the CBIS. The importance of sharing meanings and communication in IS design is discussed in further detail in Chapter 9.

6.3.2 How does the existing DHIS assist with the assessment of the situation of children's health and in identifying action to be taken with respect to the vision of the community?

From the community meetings, situational analysis and assessments, community members felt that, even though, some of the data items in the existing HIS were relevant, most of the data items were externally determined. The process of identifying community indicators to be included in the IS was therefore critical in order that progress towards the vision could be measured.

6.3.3 How can information flows be designed that facilitate the integration of the CBIS with the formal health facility IS?

The discussions showed how important the changes in the information flows were, but perhaps of greater relevance, were the suggested changes in the format of those flows. The Community Field Facilitators in the UThukela District were key in this respect. They already had the connections with the local government structures and therefore carried out the focus group discussions in local communities and in familiar surroundings. Following on from the FGD's training in child development and care at a household and community level commenced, as this was a request from the participants of the FGD's. This will enable those acting on the Clinic Health Committees to become a resource for the community they serve. All participants and members of the health committees are volunteers - refunding of travel expenses was given for attendance at the focus group discussions.

Participation without relevant information is difficult, thus the 'feedback pathways' of relevant health information were reviewed to include community level structures and also to be integrated into the existing DHIS. There is a wealth of talented story tellers, singers and poets in the UThukela District. Many of these people are willing to be involved in the dissemination of information in a more creative way than is currently applied to health data. Networking of key community duty bearers has the potential to improve through their participation.

Measure	Suggested questions/observation for collection of data
Physical health /IMCI danger signs	Is the Road to Health Card available? Is immunisation schedule up to date? Is child exclusively breastfed? Does caretaker have knowledge of danger signs (using family booklet as communication tool)? Record of births (including low birth weight, place of birth, full term delivery or not) Record of deaths (age and cause)
Growth	Record of good, faltering or failure
Active/plays	Ask mother whether child is active and about the developmental milestones. Observe
Happy	Observe
Drug/alcohol abuse by parents	Ask questions (indirectly choose topic on alcohol/drug abuse and discuss it together) Visit home at different times of the day and observe: Is child neglected?; Can you see smoke or smell dagga?; Does caretaker show signs of alcohol or dagga abuse?
Communication between parents	When have a family discussion do all family members participate in the discussion? Are you approached by any family members after the discussion offering an explanation of the situation? Ask who makes the decisions and other questions concerning communication in the household?
Love	Observe
Food and nutrition	Observe by looking at the family's health Is there a vegetable garden? What is the growth of the baby/child like?
Hygiene	Observe What type of latrine/toilet does the household use?; How is rubbish disposed of?; Is there soap in the house?; Is child washed and are his/her clothes clean?
Water	Observe if there is a safe supply of water?
Housing	Observe condition of house (windows, ventilation, roof, number of people living in house)

Table 6.5: Community Health Worker response on how to measure community indicators

Chapter 7

Output of the Community-Based Information System

After the recommendations on changes in the DHIS were suggested by the research team to the District Department of Health, a number of changes were made in the system. This chapter details the changes, which included community-based measures and indicators, new data collection tools, forums for discussion and reflection and changes in information flows and communication loops. As with any action research cycle, revisions to the system are still being made and further evaluations will take place in the future. This chapter addresses the research question: **What changes have occurred, in terms of highlighting the health status of children, in the community and the health systems, since the new IS has been introduced?**

7.1 Introduction

It is difficult to identify which changes could be directly or solely attributed to the research, as many other activities took place at the same time and the context is continually changing. However, there were changes to the IS at a local level that did take place in this period which were clearly attributable to (and impacted on) the research conducted. In terms of sustainability many of the new features built on existing structures, for example the revised Community Health Worker tool and the use of the village health days as an important component of the information flow.

A number of changes in the DHIS were planned and implemented based on the research undertaken. These included the determination of the community's indicators, changes in data collection tools, creation of forums for analysis and reflection and changes in the information flows and communication loops for improved feedback.

7.2 Determination of the community's indicators

One of the aims of the process of developing the child-health CBIS is the development of the capacities of the community to highlight and create awareness of the situation of their children and to be able to act based on that information. It also aimed to highlight the situation to the district and provincial authorities to help make the situation of children better through more effective interventions based on the improved information and community demands. The research identified that while some data for 'at-risk' and 'well-being', such as children's growth and immunisation status, is currently collected in the DHIS, this data is not being relayed back to the people responsible for taking action. Furthermore, other data sources, such as the surveys conducted by the local municipality, routine data by the environmental officers, census and the South African demographic and household survey are not used. Most importantly, the research showed that what was also absent from the DHIS were indicators of the context which shapes the status of children, such as good communication between parents and children, love or societal norms and values. This type of data cannot be collected through 'facility-based' HIS, but needs to be largely articulated by the community. Some of the suggested indicators to measure vulnerability, or 'at-risk' and 'well-being', based on discussions with

the district health staff, project staff, community representatives and Community Health Workers, are given in Table 7.1 (CHW = Community Health Worker).

Measures from field work	Examples of Indicator	Source
Physical Health (IMCI danger signs)	Immunisation coverage under 1 year	Routine Clinic Data
	Measles coverage under 1 year	Routine Clinic Data
	Incidence of diarrhoea under five years	Routine Clinic Data
	Proportion of care-givers knowing 2 or more IMCI danger signs	CHW data
Growth	Number of deaths by age	CHW data
	Proportion of children visited whose growth is faltering or failing	CHW data
	Proportion of children growing well	CHW data
	Low birth weight	CHW data
	Full term birth	CHW data
	Birth at health facility	CHW data
	Good weight at birth	CHW data
	% babies exclusively breastfed	Survey and CHW data
Active and/or Plays	% of children who are active and plays	CHW data
Happy	Proportion of children who appear happy	CHW data
Relationship of parents	Good relationship between parents	CHW data
	Good relationship between child and parents	CHW data
Drug/alcohol abuse of parents	No evidence of drug/alcohol abuse	CHW data
Love	Child was planned	CHW data
	Loving household	CHW data
	Baby looked after	CHW data
	House in good condition	CHW data
Hygiene	Proportion of families with access to and type of toilet	CHW Family card
	Proportion of families who dispose of faeces safely	Survey and CHW data
	Proportion of families who have soap in their homes	CHW data

Table 7.1: Developing the community indicators

The indicators from this list that are sent to the health District Information Officer, include total births at home, number of child deaths, children not immunised, number of children referred and growth indicators (faltering, gained and lost weight). The data definitions for these indicators are common between the health

facility staff and Community Health Workers. Depending on the child-health priorities of a particular community, the relevant data is relayed back to the community by the Community Health Worker through song, dance, charts and role plays at village age days.

7.3 Changes in data collection tools

The newly designed Community Health Worker household observation form includes questions related to the information the community wanted included in the IS and was a revision and condensing of the previous five different data collection forms. The revised form includes questions which 'assess' the current status of the child, as well as the context the child is living in. The tool was initially piloted by 5 Community Health Workers in 2 municipalities and based on their comments the tool was adapted. All (seventy five) Community Health Workers in OKhahlamba Municipality were then trained on the new data collection tool. The date for the use of the tool was set and after one month of use the tool was again revised and clarifications made on the data items.

From this observation form (see Appendix A) data items such as weight, immunisations received, deaths, births, hygiene, presence of parents, alcohol and drug abuse, happiness of child and communication within the household are collected. At the household level, the Community Health Worker uses the observation tool as a communication device with the household members. Based on the Community Health Workers' assessment a number of choices or options to solve any of the problems identified is given to the household. The Community Health Worker could facilitate the choices made by the household, such as contact with certain services, if requested to do so. The assessment is used as an empowering tool rather than as a means of inspection. These visits assist the care-givers in terms of their knowledge of child-care and health-seeking behaviour within their household. The Community Health Worker has the potential to act as a mediator, both between the mother/care-giver and the health facility and the Community Health Committee, as well as between the mother/care-giver and her/his family. The photograph in Figure 7.1 shows a Community Health Worker visiting a household and weighing the baby. Praise is given for achievements made, such as the good growth of the child.



Figure 7.1: Community Health Worker weighing child during household visit

The Community Health Workers were generally very positive about the new tool. This was for a number of reasons. The main one being that that the previous 5 forms they completed were reduced to 1. Further, the summary of the data collected was done after each visit on the end of the form and then a summary sheet was filled in at the end of the week. This meant that, when they came for their monthly meetings, they already had their summary for the month calculated and the collation of the data took 1 hour instead of 3 or 4. This afforded more time for discussion of the data and other issues. Most importantly, there was recognition that the data and work they did was being recognised by the community and by the district.

7.4 Creation of forums for analysis and reflection:

The initial discussions around the development of a vision for the children of the district started a communication process that developed further. There are three

forums or spheres for discussion of the data and reflecting on and learning from it: the household, community and district spheres.

At the household level, the Community Health Worker uses the observation tool as described above (Section 7.3) to assess the 'well-being' or 'risk' of children in that household on a monthly basis. The observation tool is used to assist the health worker in making her assessment and on which to base the discussions with the household. Based on the observations, the health worker discusses the situation with the care-giver present. Advice is given, possible solutions identified, referrals made and assistance provided in carrying out the decisions of the household if needed.

At the community level, the Community Health Workers, with the assistance of their supervisors (the Community Health Facilitators), conduct village health days for discussion of broader issues affecting the community served by the clinic. Experience has shown that the use of a variety of media, such as bar graphs, role-plays, song, poetry and dance has been very effective in this context. The photograph in

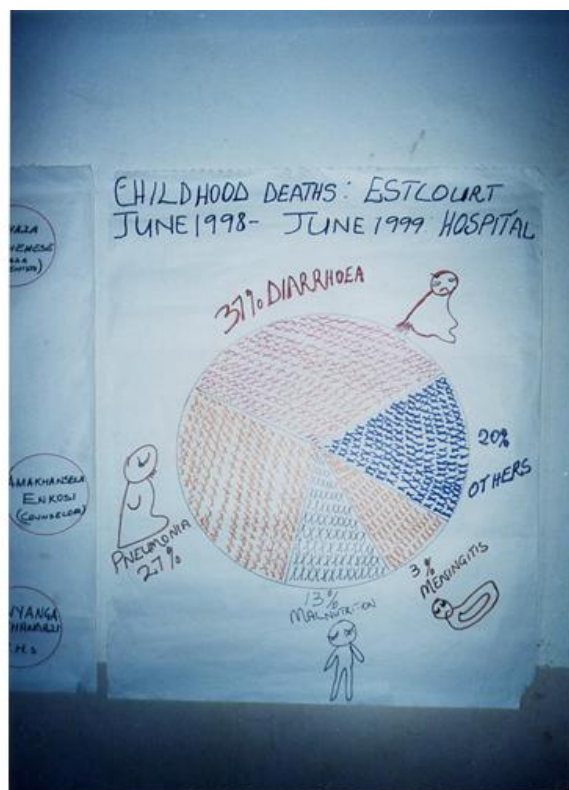


Figure 7.2: Causes of childhood mortality

Figure 7.2 shows a poster indicating the causes of childhood mortality from hospital statistics presented to the community at one of the health days. These health days are very celebratory in nature and build on the strong musical and dance skills of the community. Members of the community and the Clinic Health Committee, health facility staff, Community Health Worker, school children and other key people attend the meetings.

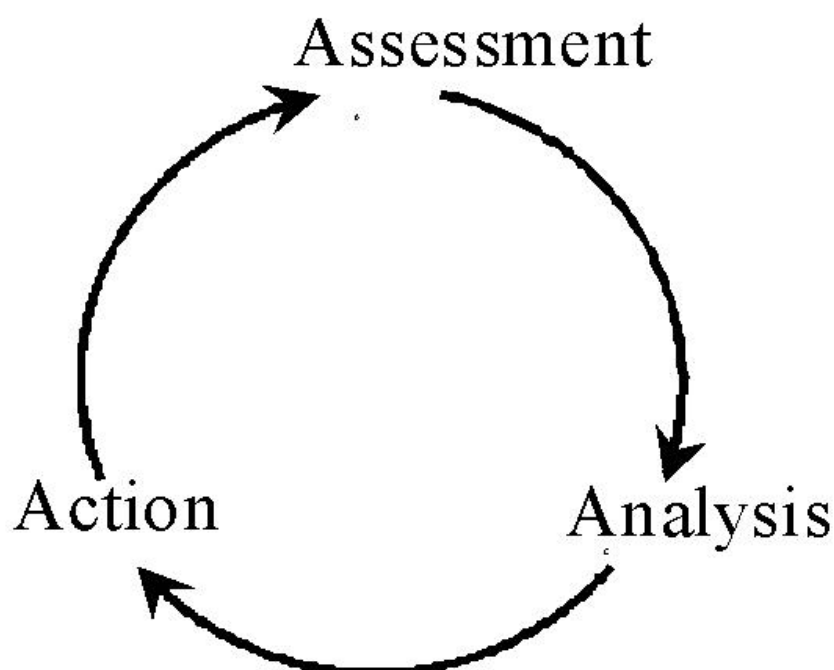


Figure 7.3: Triple 'A' cycle

A salient feature of the system is that it has been implemented by building upon the traditions and culture in practice and, therefore, is primarily a paper and oral based system. An example of this is the feedback to the community of the data collected by the Community Health Worker. Parents, children, district health staff, councillors, teachers, Clinic Health Committee other interested parties are invited on a monthly basis for feedback of the data collected from their village in the previous month. Community halls or school classrooms are used as the venue. The session commences with prayer and is opened by the councillor. Through

the use of song and dance the various roles of the people involved in health are explained and people are introduced. The topic for the day is then explained, for example it may be on TB, and through discussion, role play and question and answer sessions the topic is discussed. The Community Health Facilitators and the Community Health Worker for that village present the data using pie charts and histograms on flip chart paper. They explain the data they found, ask questions on why this is the case and discuss the possible action that can take place to improve the situation for children. Children sing songs and dance to express their views and concerns on health issues. Participants express their understanding through words sung to the tune of a familiar hymn accompanied by traditional dances. The day is very celebratory in nature and is closed by the chairperson of the Clinic Health Committee who summarises the days' proceedings and agreements made.

The village health days strengthen a learning process approach, which encourages critical reflection and is linked to action. The learning process builds upon existing community skills and resources, their talent for song and dance, and on their knowledge and practices. Each step in the cyclical process of Assessment, Analysis and Action (more familiarly called the Triple 'A' Cycle as illustrated in Figure 7.3 [UNICEF, 2000]) is dealt with in turn. Time is given for discussion on each issue raised. The need for action is often discussed in these meetings and types of action are identified, but currently no mechanism exists for monitoring the implementation of the agreed upon decisions. The same Triple 'A' Cycle is used in the monthly Community Health Worker meetings.

At the monthly meetings, the Community Health Workers submit their data to the Community Health Facilitator. The photograph in Figure 7.4 shows the Community Health Workers compiling monthly statistics. This is first done on an individual level where each health worker sits with the respective facilitator and discusses their data and issues that have arisen during the course of the month.

After each individual health worker has submitted their data, one of the Community Health Facilitators (there are two for the municipality) presents the collated data to the group of health workers. The photograph in Figure 7.5 shows the Community Health Facilitators collating the Community Health Worker monthly statistics. After the assessment is presented the data is analysed collectively in order to gain greater understanding of the situation painted by the data and also to identify or clarify any unusual patterns or trends. In the ensuing group discussion possible



Figure 7.4: Community Health Workers compiling statistics at their monthly meeting

action for the next month is identified and concerns are raised and possible solutions found. Positive lessons learnt and experiences are also shared. The summary data for the wards is submitted to the District Information Officer by the Community Health Facilitator.

The next sphere of communication identified is the district level. Communication and information flows between community and district involve combining data from various sources to provide a comprehensive database for the district. Important for the collation of this data is the use of the same data definitions in the different data sources. This collation should be done through the District Information Officer as it is this office that receives the data from the different sectors. It was suggested that the District Information Officer should summarise this data in a simplified manner and distribute it every quarter to those who submitted the data. Existing local government structures, Community and Clinic Committees, have already established clear communication channels with the higher levels of



Figure 7.5: Community Health Facilitators collating monthly community-based data

local government. The feedback from the village health days could be sent through these structures when needed. Thus, a comprehensive picture of child-health in the district can be achieved. Given that the position for District Information Officer had been vacant for the duration of the research (approximately three years), the flow between the community and the District Department of Health had not taken place by the time of writing. Currently information is relayed back to the health facilities and electronically to the province and District Health Management Team by the newly appointed District Information Officer.

7.5 Changes in the information flows for improved feedback

The child-health CBIS is primarily a paper and oral based system with a number of revised data and information flows. Community data is collected through the

Community Health Workers monthly visits to the households and relayed back to the community through village health days. The aggregated data is compiled by the Community Health Facilitator and is sent to the District Information Officer who includes the data for each municipality in her monthly feedback reports to the health facilities and district programme staff. At the district level, the data is entered into a computerised system and is also sent electronically to the province for further transmission to national level.

Two important information flows, which build on the above communication loops, were identified. The term 'feedback pathways' was coined by one of the Project leaders to describe these flows. The core 'pathway' at community level is between the Community Health Worker, the Clinic Health Committee, the household and the clinic. The format of this flow is done in a culturally acceptable way. This flow is shown in Figure 7.6.

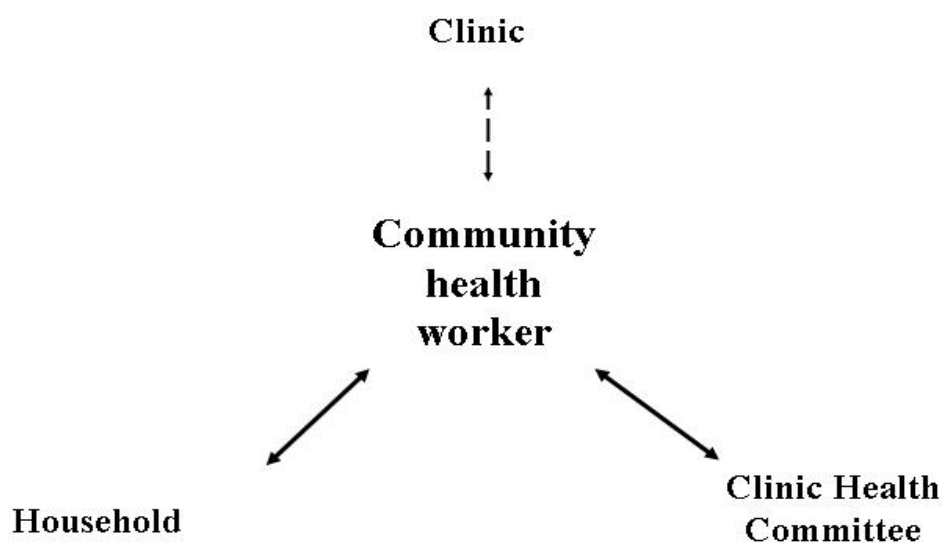


Figure 7.6: Proposed community information flows

The use of the Community Health Worker observation tool enables the Community Health Worker to identify any challenges or problems faced by the house-

hold and, through discussions, identify possible solutions. The Community Health Worker is in a position to request assistance from the Clinic or Community Health Committee if needed. The assessment tool facilitates appropriate action to take place. The Community Health Worker can also use the clinic health statistics to make a more informed reflective decision.

The second 'feedback pathway' operates at a broader level, to include data from various sources to create a more comprehensive database for the district. This collation would be done through the health District Information Officer as this is the office where the data should be received. As the District Information Officer has only been appointed in September 2003 this had not occurred by the time of writing. This flow is illustrated in Figure 7.7.

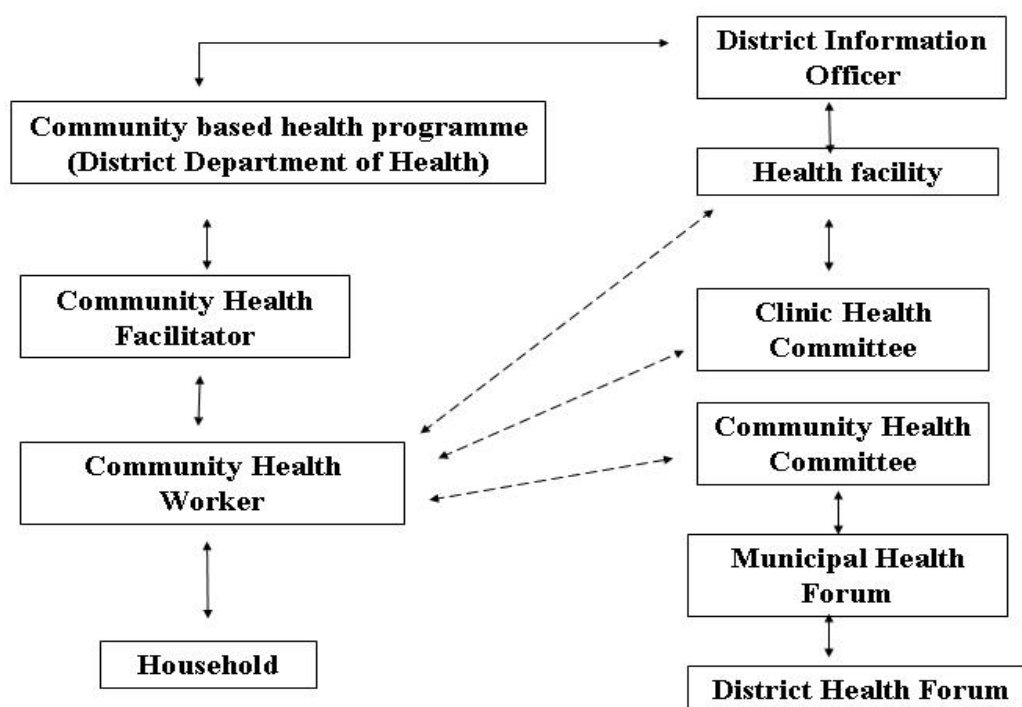


Figure 7.7: Proposed District information flows

7.6 Conclusion

In summary, there were four main changes to the DHIS which can be attributed to the CBIS research:

- Community determined indicators were included into the new IS. This meant that, in addition to the existing indicators which described the physical condition of the child, indicators which described the context of the child were also included.
- In order to collect the indicators for the context, the existing Community Health Worker data collection forms were adapted for this purpose.
- To stimulate reflection and use of the data, different forums for analysis were strengthened. The monthly Community Health Worker meeting now includes both individual reflection on the data, as well as group reflection on the data, before monthly plans are developed. The village health days involve a process of Assessment, Analysis and Action (the triple 'A' cycle) on the data presented to them by the Community Health Worker.
- There were changes in the information flows. Households received feedback immediately from the Community Health Worker during her visits. Communities were given feedback at the village health days. Though the community-based data is not available for each health facility due to the differences in the catchment areas, the health facility staff will receive the information aggregated at municipal level. The newly appointed District Information Officer is investigating the possibility of generating data from the Community Health Worker data that corresponds to a health facility catchment population.

Part IV

Analysis and implications of research

Chapter 8

Rethinking participation

Despite the tremendous potential that IS provide in supporting PHC functioning, the design, development and implementation of these systems is a non-trivial task. Stories abound of IS that have failed to deliver the promised potential. Conditions of complexity in the PHC system make the task of design, development and use of IS for PHC, especially in the context of developing countries, a very challenging task. An important step in trying to address this complexity is to enhance participatory processes of various stakeholders. Whilst acknowledging the contribution to research of participatory design (PD) in IS, the approach adopted in this case study emphasises the need to reconceptualise the idea of participation in IS design from a human rights perspective in order to accommodate the community's right to participate, the need for a multi-level and multi-sectoral approach, the politics of participation and 'non-participation', and the need to develop capacity for participation.

This chapter addresses the research question: **What role does participation play in the design of a CBIS that supports the realisation of children's right to health?**¹

¹The content for this chapter is adapted from the paper written by E. Byrne and S. Sahay. Health Information Systems for Primary Health Care: Thinking About Participation. In M. Korpela, R. Montealegre, and A. Poulymenakou, editors, Proceedings of the IFIP TC8 & TC9/WG 8.2 & WG 9.4 Working Conference on Organizational Information Systems in the Context of Globalization, In-Progress Research Papers, Athens, Greece, pages 237-249, 2003. The content of this chapter also contributed to the discussion of participation in the paper by S. Puri, E. Byrne, J.L. Nhampossa, and Z. Quraishi. Contextuality of participation in IS design - a developing country perspective. In Proceedings of the PDC04, The Eighth Participatory Design Conference, Toronto, Canada, July 26-31 2004.

8.1 Introduction

PHC is the approach adopted by the Government of South Africa in the delivery of health services since 1994. PHC systems are organisationally complex, comprised of multiple levels of hierarchy and various vertical health programs (for example malaria and TB). Aspects of history, geography, culture, infrastructure, inadequate skill levels and pressures of everyday work further heighten the complexity. These conditions of complexity in the health system make the task of design, development and use of IS a very challenging one. An important step in trying to address this complexity is to enhance participatory processes of various stakeholders in the design, development and use of IS. This point, though largely acknowledged by IS researchers in western contexts, is only in recent years being argued for by researchers designing and implementing HIS in developing countries. For example:

The restructuring of routine health information systems should involve all key stakeholders in the design process. Experience suggests that systems that are designed by a team of 'information experts' without adequate involvement of key stakeholders usually fails to reflect the needs and practical reality of service providers and managers, and does not encourage the ownership of systems [Routine Health Information Network, 2001, p. 3].

This argument reinforces the findings of more than two decades of research in IS that has emphasised the contribution of participatory processes in the design, development and use of IS in organisations in general. However, approaches to develop these participatory processes have primarily been articulated in settings from western organisations where conditions are quite different from the developing country PHC situation. The need to develop participatory approaches that take into account different contexts, processes and situations has been the underlying theme of the recently concluded Participatory Design (PD) Conference in Malmo, Sweden (2002).

This research contributes to this call from the PD Conference by adopting participatory processes in the design of IS within the South African PHC system. Additionally, I examine the strengthening of such processes. Community participation is enshrined in the constitution and legislation of South Africa, is a fundamental principle of TDCSP and is, even in IS literature, viewed as a way to redress power

imbalances for a more 'ethical' approach to IS design. This chapter focuses on the analysis of participation in the research process and addresses the following research question: *What role does participation play in the design of a community-based information system that supports the realisation of children's rights?*

The preceding chapters have placed this research in its context, so this chapter commences with placing my research in the context of the current debate on participation in the IS field. Following this, I summarise the participatory elements of the IS design process and explore the implications of this approach to IS design more generally. The penultimate section outlines the challenges faced in adopting this process. The final section concludes by returning to our research question and outlining the benefits of reconceptualising participation in IS design in general.

8.2 Participation in IS design

Over the years, research in effective IS design has pointed out the important role of 'user participation' in the design of effective IS. This body of research has been important to help refocus the previously dominant technical orientation of systems developers, which finds its origin in a dominant computer science tradition, to also include the needs and aspirations of users, and to actively recognise the expertise the users hold. Though emerging from different settings the rationale behind its emergence is primarily twofold. On the one level, is the recognition that it is ethically and morally right that workers should be involved in the development of systems which are to affect their working lives. On another level, is recognition of the failure of the traditional technical approaches and that participation may help overcome some of these failures [Fitzgerald et al., 2002, p. 52]. Mumford aptly summarises this view of participation "Participation is viewed both pragmatically and ideologically - something that helps efficiency, satisfaction and progress but which is also morally right." [Mumford, 1984, p. 103] PD research in IS finds its roots around the mid 1970's through studies carried out primarily in Scandinavia and the UK.

Asaro summarises the European participatory approaches in IS as having two strands: the collective resource approach adopted in Scandinavia with an emphasis on union empowerment and the socio technical approach in Britain focusing on autonomy in work group organisations through power sharing, joint responsibility

and multiple leadership [cited in [Puri, 2003, p. 35]].

In Scandinavia, the first phase of the PD research was to strengthen the capability of workers to question issues regarding technological changes and threats to the workplace. Participation was by a broad based workers group. One example in this phase is the participating unions from the Iron and Metal Workers Union project in Norway [Nygaard, 1979]. The second phase also tackled the skills enhancement of certain skilled workers who were considered important to include in the participatory processes. This phase shifted toward producing technological alternatives using participatory prototyping and design techniques, for example in the UTOPIA project in Denmark and Sweden [Bjerknes et al., 1987]. Here academics and employees were, using a small scale action research approach, involved in the design of technological options for graphics workers to produce high quality products, improve skills and generally enhance the democratic ideals of the organisation. Moving from the union based projects in what may be labelled as the third phase, the focus was on the design of IS in contexts where ethical issues were raised [Bjerknes and Bratteteig, 1995]. In summary, the Scandinavian research emphasises the concerns of politics, distribution of power in the workplace, and how imbalances can be corrected through the participation of the workers.

Another stream of PD research, popularly called the socio-technical approach, evolved in the UK. An example of this approach is the development of a methodology (ETHICS) for a PD approach for the introduction of new computer systems by Mumford [Mumford, 1993]. The aim of this methodology was to assist a representative group of future systems users and technical staff to analyse their own needs and problems and develop solutions to achieve technical, organisational and social objectives. The methodology requires time to learn, social skills and the ability to transfer personal knowledge to a group inexperienced in managing change but provides long term benefits [Mumford, 1993].

In the United States there was a more limited and later adoption of the PD approach reflecting the very different socio-political conditions, especially between Scandinavia and the US. PD was primarily adopted in different proto-typing and Business Process Re-engineering (BPR) endeavours. Proto-typing reflected a focus on the needs of the customer, and hence customer satisfaction, in relation to systems developed. It also aimed at reducing design time and improving the skills of the designers. BPR aimed at more efficient and effective organisational and business

practices [Puri, 2003, p. 37/38]. On the desire for participation on a more ethical and moral basis, though not adopting a single approach to PD, the North America-based Computer Professionals for Social Responsibility has influenced public policy, facilitated conferences and assisted researchers. This group provides a platform for critical voices and politically oriented PD in IS.

By and large, in all the above approaches, participation of intended users is seen as a precondition for good design and increases the likelihood of integrating the new system into the organisation. However, in the research mentioned above, there has been limited discussion on related issues such as variations in why and how workers participated, or on the extent and type of participation within the organisation. Most of the research has focused on western societies. A special issue of *The Information Society* recognises that IS from the 'developed' world cannot be replicated in developing countries and addresses the question of how to adapt these IS in such a way to balance "... global solutions, technologies, and practices on one hand, and local requirements and institutional dynamics on the other" [Sahay and Avgerou, 2002, p. 73]. Braa and Hedberg, in an article in this issue, [Braa and Hedberg, 2002] examined the participatory prototyping of the HIS in South Africa - the HIS which has been described in Chapter 3.

Moving out of the workplace there has been, recently, debates over the involvement of community members who will be served by the health system [Braa, 1996]; [Korpela et al., 1998]. The argument in this type of setting for participation is often based on a more intuitive basis rather than on empirical grounds. However, there remains limited literature in mainstream journals on developing country experience in IS design, especially on the differences in eliciting participation from community-based settings as compared to the western workplace context.

The issue of community participation has been dealt with more comprehensively by international agencies like the World Bank and UNICEF and NGO's in development projects initiated outside the IS field, employing Rapid Rural Appraisal (RRA), Participatory Rural Appraisal (PRA) and more recently Participatory Learning for Action (PLA) methods. As mentioned in Chapter 4, participation, especially in the context of community, is intricately linked to questions of democracy, power, and asymmetries that exist within communities. However, the success of methodologies like PRA and RRA in addressing the complex socio-historical-cultural conditions have remained questionable, and various critiques have been

raised in the domain of development studies research [McGee, 2002]. Until now, these participatory methodologies have found very limited application in IS design and development projects. However, given the present context where there are increasing attempts to develop e-government applications aimed at the community, and rising concerns about the 'digital divide', the need to develop approaches to facilitate participatory approaches involving CBIS is being recognised as an important need by IS researchers [Puri, 2003].

8.3 Participation in the case study

Details of the process and output have been given in the preceding two chapters. This section summarises aspects of this process and output which specifically addresses issues of participation. The reason for the focus on participation was mainly threefold:

- The South African constitution and legislative framework provides for the participation of community members.
- The Project, TDCSP, is built upon the principle of 'genuine community involvement'.
- Community members, after the monitoring and evaluation workshop held in 2000, expressed the need for the design of an IS that addressed their needs and in which they were involved.

Various participatory techniques were adopted in the design process and are embedded in the resulting CBIS.

8.3.1 Participation in the process of CBIS design

There were three main phases, or areas, in which participation was addressed in the design process of the CBIS: identification and involvement of role players, visioning and the reviewing and revision of existing IS.

Identification of role players

As mentioned in the previous chapter (Chapter 7) key players that affect the development of children were identified through PLA sessions during the conducting of the situational analysis and assessment [Gibson et al., 1999] and reconfirmed during

a separate exercise by the research team. (The photograph in Figure 6.1 illustrates the results from one of these discussions.)

Due to the ongoing restructuring of the health services and the transformation of local government, changes in the role players occurred throughout the duration of the Project and the CBIS design process. It was important to acknowledge these changes and review the changes regularly in terms of who should be involved. Another aspect which was important in the identification of the role players was the need to examine which of the role players had a duty to perform their role, whether in terms of their work, e.g. a nurse working at a clinic, or position in society, e.g. a chief. In these cases there was the need for the duty bearers to recognise and accept their duties. Other role players could assist in the carrying out of their functions, but were not obligated to do so, for example volunteer Home-Based Carers. This process was particularly important in clarifying the roles and responsibilities of the Community Health Workers and the Community Health Committees who had recently undergone changes in their composition². Lastly, another important issue in the emphasis on the various role players involved in child-health, was the recognition that the community was not a homogenous unit. There was recognition that though the health of a child is viewed largely as a 'woman's' job', many other people, including men and the children themselves, also affected and impacted on that child's health. All these role players would, therefore, need to be involved in the design of an IS that would assist in describing the situation of children in the community.

Co-determined vision

In order for the role players to act together there was the need for a co-determined vision for child-health. In line with traditional views, the outcome of the research confirmed that the health of the child was viewed holistically. Furthermore, though participatory methods were used in defining the vision in the initial stages of the Project (see Section 6.2.2), at a community meeting there was the need to revisit this vision in other settings. Through a co-determined vision all role players

²The Community Health Workers had at the commencement of the Project been employed by TDCSP. In 2000 they were employed by the Department of Health and underwent comprehensive training and reporting structures were changed. Likewise after the local government elections in 2000 many of the Community Health Committees were reformed due to objections of the newly elected council members that the committees had not been democratically elected.

could act together in trying to achieve that vision. The IS would need to assist in measuring the progress and ultimately the attainment of that vision.

Reviewing existing HIS

The existing HIS was reviewed so that the various role players would understand the existing system and then be able to review it in terms of their needs. This was done in the meeting on monitoring and evaluation in February 2000 and gaps were identified between the existing system and what was needed. The HIS was more systematically reviewed as part of the Projects' participatory end-of-term and mid-term evaluations [Bergville District Child Survival Project, 1999a] [TDCSP, 2001]. The findings of these evaluations were relayed back to the role players through written reports, poster sessions, drama and community presentations. As many of the role players were involved in the Project evaluations they were also trained in data collection and analysis techniques, such as FGD's and PLA methods. Capacity to review and monitor future changes or activities was developed. Additionally there has been an improved awareness of what data is available and is being collected.

8.3.2 Participation in the revised HIS

Given that the CBIS was designed so that the information can be used for advocating and influencing decision making and policies for the rights of the child, participation of key role players and duty bearers in the output of the CBIS was also important. If the role players are to act based on the information, they need to be part of the information flows and communication loops of the implemented system. The way in which they are involved is also the subject of the next chapter on communication. Therefore, I will explore here their participatory role rather than the process of communication. Four main changes to the HIS were made, as outlined in Chapter 7:

- determination of community's own indicators;
- changes in data collection forms;
- creation of forums for analysis and reflection, and;
- changes in the information flows for improved feedback.

I will now briefly outline here the role participation played in each of these changes.

Determination of the community's own indicators

Focus group discussions with groups of the main role players were held near the living or working area of the participants. Community Health Workers and Community Health Facilitators were often used as facilitators of the FGD. Between 7 to 10 people discussed what they meant as 'well-being' and 'at-risk' for the child and how they would measure these terms. Using tools such as gaps analysis, where two pictures showing one happy physically healthy child and another showing a sad unkempt ill-looking child, the participants described what the differences between the pictures were and how they would measure such differences. The recorder of the FGD noted the discussions and the research group subsequently compiled the results from all the discussions. Visualisation in Program Planning (VIPP) techniques were employed to group terms and themes. This was done through cards, with the common terms written on them, being placed on a large 'sticky' cloth. Each card was then discussed and clarified by a team comprising research team members, the District Information Coordinator, the CEO of the local hospital and community members who had been involved in the discussions. Each term was refined to be more measurable, for example, the term immunised became 'a child who was fully immunised by the age of 1 year'.

In line with traditional views of holistic health, new indicators were included into the CBIS. Specifically these indicators include measures for the context in which a child lives, as well as including indicators that extend beyond the physical health of the child. Through the collection of various views on what should be included in the CBIS, an IS was designed that fitted in with traditional views and values regarding the determination of health. A discussion to develop a common understanding of the meaning of the indicators was held.

Changes in data collection forms

Once it became clear that the data collection tools of the Community Health Worker would need to change a smaller group of Community Health Workers came together with their supervisors to discuss all the data collection forms used by them. In total 5 forms were in use. As there was much duplication on the forms it was a relatively easy task to combine 4 of the forms into one data collection tool. The data items that the community members wanted collected was used as the guiding principle for prioritising the items to collect. As there are no standard tools nor

data requirements for the Community Health Workers, or community, in the formal DHIS there was no conflict between the formal DHIS requirements and what the community wanted collected. One form (the origin of which was never discovered) collected details of specific illnesses, but the form was so badly designed that the data collected was useless. This was largely due to the differing opinions on what each of the data items meant. The decision was taken to leave the form aside and wait to see if anybody noticed it wasn't being completed. If there was then a request for the data a discussion over the requirements and data definitions could be arranged. At the time of writing there has been no such request. A summary of the data items that need to be sent to the district is completed at the bottom of the page of the data collection form (see Appendix A). This was inserted following a recommendation by the Community Health Workers to have some way in which they could quickly summarise the data at the end of each month.

Once the changes had been made to the form a small group of Community Health Workers tested the form and came back after two weeks with recommendations on refinements and clarifications to be made. Once made all Community Health Workers, in two separate groups, were introduced to the proposed changes and made further changes to the form (mainly in terms of layout). The tool was then field-tested for one month. All 75 Community Health Workers came back together and further refinements were made (this involved mainly clarification over the definition of the data items). The form was then finalised and no further changes were made, though there was a proposal that the tool should be reviewed periodically.

The Community Health Worker observation tool is not simply a data collection tool, but is also used to facilitate discussion with the household. Through these discussions it is hoped that access to information at household level will improve, as well as enabling the Community Health Worker to raise issues, if needed, on behalf of the household at community meetings. Furthermore, the number of data collection forms has been considerably reduced and this has decreased the time spent collecting and collating the data. This creates more time for the Community Health Worker to analyse the data and plan the household visits. Capacity has also been developed to change the data collection tools if needed in the future.

Creation of forums for analysis and reflection

A more detailed discussion of the format of these discussions for analysis and reflection has been given in Chapters 7 and will be further discussed in Chapter 9. What is sufficient to reiterate at this point is that there are a number of platforms in which the various role players can debate the information received and reflect on possible actions or decisions. The design of these forums has been at different levels: household, community and district. Attempts were made to make them as accessible as possible (for further discussion on this point see discussion in Chapter 9, Section 9.4).

Changes in the information flows for improved feedback

Changes in the information flow were largely suggested from two stages of this research. The first was after the monitoring and evaluation workshop in February 2000. Community members realised that much information was already being collected in the DHIS and would be useful to them. However, there was no information flow from the DHIS to community members or forums. If some of the information being generated by the existing DHIS was sent to the key role players and duty bearers, these key role players and duty bearers felt that they had sufficient resources to act based on that information. Even in cases where they did not have the resources, they felt that they would be able to use existing structures to obtain them. Emphasis was placed on appropriate feedback of appropriate data for different levels. This was particularly important given that different role players had become key to the health system since the original HIS had been designed, e.g. the introduction of Community Health Workers in the district and the increased involvement of local government, especially the community-based structures.

The other important stage for recommendations on changes in the information flow was in the process of refining the indicators to be collected at community level and the discussion on the data items to be included on the Community Health Worker data collection form. In both these processes, when a data item was suggested for inclusion, the questions 'What information would this data item generate?' and 'Who can act based on this information?' were asked. In this way people reflected on the data items and realised that most of the data would only be useful for local level action and was not needed at the district level. The information flows were revised based on these discussions and showed a movement away from the pre-

vious tendency of sending all data collected 'up'. A small number of data items, as shown in the summary section of the Community Health Worker observation form (see Appendix A), was chosen to be sent to the health facility and the district.

8.4 Discussion

Against this background I explored how the way in which participation was conducted in this case study differed to that explained above in the contemporary debate of participation in IS design. The four main main departure points are:

- obligatory community involvement;
- the need for a multi-level and multi-sectoral approach.
- the politics of participation and 'non-participation', and;
- the need to develop capacity for participation and for developing a climate for learning.

Each of these points is described in more detail below.

8.4.1 Obligatory community involvement

As mentioned above, while some authors have argued for the need for PD in developing countries from a community perspective rather than a workplace context [Korpela et al., 1998] [Braa, 1996] there is little documentation of this actually happening in practice. This research strongly emphasises that the need for community participation cannot be ignored, especially when it is an obligatory and normative requirement. This emphasis has historically been an element since the early days of the RDP and is enshrined in the constitution and local government legislation. There is the recognition that government service providers and the communities are partners in the delivery of social services. For this effective partnership there is the need to share relevant information and knowledge about their situation. Through co-determining a vision and creating a forum for open and equitable debate and discussion this participation was attempted.

As seen in the case study, the context in which a child grows up is important to monitor if action is to take place before a child ends up in 'at-risk' situations. People outside the community do not have access to this information. Community linkages

are essential here. In order to make decisions around the situation of children a CBIS needs to link with the health facility IS to form a comprehensive DHIS.

8.4.2 Need for multi-level and multi-sectoral participatory processes

The identified role players who affect the development of a child represented both multi-sectoral (health, education, welfare and local government) and multi-levelled (household, community and district) groups. An IS that would then support these key players, and take their interests and concerns into account would necessitate a multi-levelled and multi-sectoral approach and address the different levels of interdependencies. Indicators for holistic child-health covered areas concerned with education, infrastructure, social welfare and employment. It was important not to duplicate existing systems, but to build upon what was already there. Linkages between the existing DHIS and the data held by the local municipality and various other departments would be needed if a comprehensive DHIS is to be achieved.

The first step identified in the participatory action research conducted here was the creation of a shared vision. But the determination of a vision needs to fit in with the various visions of the different levels and different sectors. If the visions of the various parties involved differ radically it is not possible to generate a common group action theory and framework. As Walsham notes in terms of specification of requirements for IS design “The use of participative design methods, in the absence of a shared vision for change, may not generate a consensus for action.” [Walsham, 1993, p. 203] So as the research progressed and interest grew amongst the key role players, a more multi-sectoral and multi-levelled platform was created.

Conventional PD approaches have explored IS design in one organisation and in some cases even between different hierarchical levels with that organisation, but have rarely analysed the use of PD between different organisations from different sectors of the economy. Communication between the Department of Health and the local authorities is especially important in South Africa. With the move towards the decentralisation of health service delivery a more multi sectoral IS is required. Furthermore, the established community structures, such as the Community Health Committees and Community Health Forums, have meant a negotiation of roles and responsibilities at the community and district level. This has implications for new kinds of interests and functions being reflected in the DHIS. This required active

communication between the parties involved and their participation in its redesign.

8.4.3 Politics of participation and 'non-participation'

Constitutively and legislatively the functions of IS have changed since 1994 in South Africa. In opposition to a top-down system the need for community participation in local government and the delivery and management of health services is now made explicit. However, changes are not only affected by the legal norms. As Giddens' notes processes of human interaction in terms of communication, power and both legal and social sanction all affect the structures which occur over time and space [Giddens, 1984]. One of the most important contributions of participation in the IS design and development process is that existing power structures can be made explicit and more democratic negotiation processes can occur. From a Critical Social Theoretical perspective, in this case study, the additional desire is that participation will also improve the situation of children through using power constructively. The argument being that changing the IS is a necessary, but not a sufficient, condition in changing structures of power and domination and that there is also the need for commitment and support from the government and society for structural changes to be made. One way of achieving the latter is to provide community members with the information that they could use to hold government and society accountable.

In OKhahlamba Municipality, the initial step taken was the creation of a common vision for the development of their children. As the key players who affect the situation of children were identified, they were included in the discussions on how the IS could best serve their needs. Only if the participants felt that the IS could benefit them in their day to day lives would the IS be effectively utilised. Indicators were co-designed between the Department of Health, local government, community members and Project staff. A distinctive input from participants from the community was that they were not looking to define absolute values to be placed on childhood 'well-being' or 'at-risk', but rather to be sensitive to the need to track changes in this status, to identify when action was needed when a child was seen to run the risk of danger. The HIS designed with health facility staff was more indicator and quantification driven. The child-health CBIS is less focused on absolutes and quantities than is the health facility IS.

The move towards local authority delivery of basic social services and the creation of new structures meant that many new role players were brought together

who previously were not connected. Data flows in the old system did not correspond to the new roles. Most of the difficulties in terms of participation were over the clarification of new roles and responsibilities. This demonstrates that IS design and development is essentially a process of negotiation, based on the premise that different stakeholders will have varying claims, concerns and issues, which in turn are shaped by the context-specific values of the different stakeholders.

Through the research more people were made aware of what data is being currently collected and what is of use to them. Sen explains how decisions made depend on the informational base and indicators selected [Sen, 1999, p. 54/55]. So who decides what data to collect is an important influence on decision-making. Equally important to what is in a HIS is what is absent. In our case study indicators regarding the context of the child were absent. Through discussions, agreements were reached on who should receive which data. These linkages are to be facilitated by, what one Project leader described, as a 'feedback pathway' of data. There are many of these pathways at different levels, but the one between Community Health Worker, Community Health Committees, health facilities and households is core and was absent from the previous DHIS. By creating forums for analysis and discussion information generated through the IS can be used for action and can assist in an improved knowledge base which can be used to put pressure on government and civil society to change the situation children live in.

8.4.4 Developing the capacity to participate and to take decisions

One issue that is often neglected in the literature on IS design is how the information is to be used, and the capacities or capabilities to use this data once it is collected. In our case study we explored capacities to act based on the information that the participants wanted included in the CBIS. The constraining factor for action was largely believed to be solved through the reworking of the information flows and the development of communication loops.

The ability to claim a right, or fulfil duties, requires the individual to have the capacity and information to recognise the right and that which needs to be done by the duty bearers to realise it. For actors to participate in dialogue, there is the need to recognise the structural conditions that are required for such a dialogue to take place, and what the constraints are to achieving this. Capacity development

is required to overcome these constraints, which goes beyond the skill enhancement addressed by Ehn [Ehn, 1993] and tackles issues of responsibility, knowledge and access to resources [Jonsson, 2000].

Responsible adults must be in charge of their own well-being; it is for them to decide how to use their capabilities. But the capabilities that a person does actually have (and not merely theoretically enjoys) depend on the nature of social arrangements, which can be crucial for individual freedoms. And there the state and the society cannot escape responsibility [Sen, 1999, p. 288].

Arrangements were made to enable people to participate in the design process through use of the local language, having meetings near where they lived or worked, having a facilitator they trusted and further having training on data collection methods and analysis, as well as orientation on child-health issues. This was to achieve some uniformity of the basis from which all participants were negotiating, discussing and reflecting.

Key in this case study in terms of having the capacity to act was access to information. Becoming part of the current data flow and developing a community level information flow were viewed as fundamental for the capacity to act. Clarification over roles and responsibilities was also an essential element of the process. The recent move to decentralisation of the health services to local government added to this initial confusion over roles and responsibilities. Communication was key in resolving the issues.

Being able to access information and participate in communication systems are crucial for people and organisations in the operation of their individual and collective decision-making cycles. Part of this capacity development is the strengthening of a learning process approach, which encourages critical reflection and is linked with action. The learning process is built upon existing community skills and resources and on what people already know and do, such as including existing community structures and meetings in the 'feedback pathways'. It was encouraging to see that many community participants felt that they could act if they were connected with the data flows. The monthly Community Health Worker meetings and village health days focus not just on data collected and interpreting the data, but also reflect on what needs to happen to remain in a status of good health or to change a situation of poor health.

8.5 Challenges still to be addressed and conclusion

There are still challenges that need to be addressed in the UThukela District in terms of CBIS implementation. Perhaps the main challenges are the sustainability and scalability of such a resource intensive process. These are much larger issues than just addressing participation and are dealt with more extensively in Chapter 10 and Chapter 11. However, adopting a participatory process has implications in terms of resources, both human, time and finance, often more than a district can typically be expected to have. Even in the UThukela District the system was only implemented in one municipality. The District Information Officer has indicated that the CBIS will be implemented in the rest of the district using existing structures. For this reason guidelines on the main practical lessons from this case study have been developed to assist other districts in the implementation of similar initiatives.

In terms of the process recognition of the different social groups and power differentials between groups is not sufficient to address them. So though forums were created to make participation in the design process, and in the output of the CBIS, as easy as possible, once all the role players were all put together participation was very one sided. Community members and people working on community-based interventions were largely passive in the presence of district staff and Project managers (See Chapter 9 for further discussion.) Traditional norms and views of hierarchy will take a longer time to change. What is hoped through this design of the CBIS is that linkages between the levels and groups can be made and discussion around the attainment of a co-determined vision can occur. Through continued interaction communication can improve.

Table 8.1 summarises the main points of departure from conventional approaches to participation in IS design, what was achieved in this case study and what are the challenges still to be faced.

Returning to the research question: *What role does participation play in the design of a community-based information system that supports the fulfilment of children's right to health?* Participation is fundamental to the development of a sustainable IS. However, in the area of PHC, as illustrated in the case study, there are a number of important departures from how participation has been conventionally perceived in the IS field. These are the obligatory nature of community

Point of departure	What was achieved	Challenges to be addressed
Community involvement obligatory	<p>CBIS implemented in one municipality</p> <p>Agreement to expand to the rest of the district</p> <p>Guidelines on how to develop CBIS developed</p>	<p>Need to expand to the rest of the district</p> <p>Issues of scalability of CBIS to be addressed</p>
Multi-level and multi-sector approach	<p>Co-determined vision</p> <p>Good participation of Department of Health and community members</p>	<p>Need to have other sectors, besides health, involved at district level</p> <p>Information flow and feedback between community structures and district need to improve</p>
IS design as political	<p>Community determined indicators, tool design, information flows and communication forums</p> <p>Legislative environment supportive of greater community involvement</p>	<p>Traditional positions of hierarchy and social inequality still inhibit participation in mixed forums</p>
Capacity development	<p>Skills developed in data collection and analysis</p> <p>Used existing structures where possible to improve sustainability</p>	<p>Capacity outside case study area needs support</p> <p>Commitment and allocation of resources needed at district level to continue</p>

Table 8.1: Rethinking participation and challenges to be addressed

involvement; the need for a multi-level and multi-sectoral approach; the politics of participation and 'non-participation', and the need to develop capacity for participation and for developing a climate for learning. Obligation of the duty bearers to realise the community's right to participate necessitates community involvement. If the CBIS is an integral part of the DHIS a shared picture of, not only what health services deliverers want to see, but also what community members want to be shown can be created.

Chapter 9

Constructing local meaning - communication in IS design

Understanding the role of communication is key to changing the context regarding the situation of vulnerable children as structures are recursively and discursively reconstructed. Communication goes beyond language and the importance of translation of terms and concepts used to negotiate between different meanings and logics is explored in this chapter. In striving for the 'Ideal Speech Situation', or in other words, creating an enabling environment in which people can debate and discuss on equal terms, there is the need to develop a codetermined vision, to understand local meanings for childhood illness, to understand communication systems and the context in which they occur, and to connect with the networks outside of the localised setting such as the provincial or national authorities. This chapter addresses the research question: **What role does communication play in the design of a CBIS that supports the realisation of children's right to health?**¹

¹The content in this chapter forms the basis of a paper written by E. Byrne and J. Gregory, Co-constructing local meanings for child health indicators in community-based information systems: the UThukela District Child Survival Project in KwaZulu-Natal, in *Proceedings of the ITHC 2004 conference: To Err is System*, Second International Conference, Portland, Oregon, USA, September 13-14 2004.

9.1 Introduction

Translation of terms and concepts used in different knowledge systems by different communities goes beyond language. In designing IS there is the need to negotiate between different meanings and logics held by the various parties involved. Finding collaborative means for such negotiation and translation becomes even more acute in CBIS. To enable reciprocity of meaning and mutual construction of common ground, possibilities for public gatherings need to be established in which clients, citizens and those responsible for health service delivery feel comfortable to participate, share understandings and reflect on the dialogue of the various parties. Working across different types of knowledge entails the understanding of the different paradigms and philosophical approaches of the parties involved [Suchman, 2002];[Verran, 1998];[Puri, 2003]. Working in the area of HIS at community level, contradictions can emerge between the traditional positivist medical focus on quantitative indicators and measurement, and local or indigenous knowledge, beliefs and understandings about the causes and remedies for health problems and the meaning of 'vulnerability' and 'risks' to health. Interpretivist participatory approaches adopted in the social sciences and human development fields, combined with socio-technical understandings of IS in health care, can facilitate co-construction of local meanings, as a crucial step towards building bridges for reciprocal knowledge-sharing between different knowledge systems.

The process and results of IS design should assist in the development of a common ground for communication between service providers and clients of the health system and should foster critical reflection. The underlying structures which enable, or constrain, the potential to enter into respectful dialogue between the concerned parties, need to be explicitly analysed, in order for agreements to be worked out regarding what actions to take on behalf of the health, well-being and development of children and families. In this chapter I explore how the search for the common ground, facilitated through developing a common vision and striving for mutual understandings of health practices and local meanings for health, enabled a child-health CBIS to be implemented successfully in one municipality. I make use of Habermas' concepts of the public sphere and the 'Ideal Speech Situation' to develop a framework that highlights important principles concerning communicative action and by which communication within IS design can be taken into account and evaluated.

This chapter is structured as follows. Firstly I explore the theoretical Habermasian concepts of the public sphere and the 'Ideal Speech Situation'. Using the criteria for the establishment of the 'Ideal Speech Situation' I analysis how communication was addressed in the case study. I conclude with the challenges faced in the process and what was achieved.

9.2 Theoretical perspective

As mentioned in Chapter 2, Section 2.2.2, key concepts from social theory, particularly the concepts of the public sphere and the 'Ideal Speech Situation' from Habermas [Habermas, 1989], were used in conducting the research reported here and in analysing the changes made to the HIS in the UThukela District. Habermas' emphasis on the importance of language and communication in the attainment of an enabling environment and supporting democratic processes is consistent with the practical and theoretical approach to communication in the case study.

Relying on the historical movement in the 17th and 18th centuries of coffee houses, societies and salons becoming central places of public debate and discussion of political concerns, Habermas developed his idealised notion of the public sphere. The idealised public sphere does not necessarily exist in any identifiable physical space. Through such a forum, citizens could freely exchange views with one another on important matters concerning them. In this way public opinion could be formed. The most important aspect of the creation of the public sphere is the process of discussion. The basis for establishing consensus is on the strength of argument of individuals as rational beings. Criticism is vital in this process so that proposals can be tested and meanings can be jointly explored. All discussion takes place with the goal of developing mutual understanding and it is assumed that citizens possess the communicative competence to bring about such understanding. Breakdowns in communication occur, but it is possible for actors, through critical reflection, to come to understand the situation and the actions. Subsequently, they can either take corrective action, or can enter into discourse with the concerned parties, to clarify or rectify the situation. Three criteria for the emergence of such a public sphere are:

- disregard for status;
- domain of common concern, and;

- inclusivity. [Habermas, 1989, p. 36]

For Habermas, the success of the public sphere was founded on rational-critical discourse, where everyone is an equal participant and the supreme communication skill is the power of argument. Communication is the means not only for finding out what individuals have previously decided or learned, but also as a process in which opinion and consensus are created, by the process of debate itself. [Thornton, 2001]

A legitimate decision does not represent the will of all, but is one that results from the deliberation of all. It is the process by which everyone's will is formed that confers it legitimacy on the outcome, rather than the sum of already formed wills (quoted in [Kellner, 2004]).

An important aspect in striving for the 'Ideal Speech Situation' is to create the awareness and understanding of the various forms of domination so that people can act to eliminate them. Habermas [Habermas, 1987] distinguishes between the use of critical theories to initiate a process of self-reflection among human actors and the actual selection of appropriate political action. While critical researchers are clearly responsible for the former, Habermas suggests that only participants in the community can carry out the latter task. In communicative action, in order to make an informed decision, a human actor needs to know how to distinguish between the false and the rational debates and consensus reached. Individuals and institutions can act strategically and can thus manipulate the means and content of discourse.

One initial problem that may be observed in the Critical Social Theory approach . . . is that the idea of 'burden of proof' has a political power component that may be also an ethical one. What if those powerful agents who organise the negotiations and who ought to feel embarrassed by polemical questions do not feel embarrassed? What if they, instead, state for example that 'We find that it is too expensive to bear the burden of proof that you want to impose on us' or 'It is too expensive to elicit the voluntary consent by all those who might be affected by the system and its consequences', etc. [Ivanov, 1991, p. 9].

In this type of forum, access to information is key, as is the ability to access the discussion forum and also the capability to participate in the debate. This argument

is important especially to groups of people and sections of society that are usually excluded from such debates, such as women and children.

There are a number of implicit assumptions in this argument. Firstly there is the assumption that human beings are rational. Habermas does not address the notion that human beings are not always rational beings.

Unconscious drives, desires, fears and conflicts underlie much public communication, although much of it remains unrecognised and inaccessible to conscious, 'rational' examination (Dahlgren quoted in [Thornton, 2001, p. 29]).

Secondly, there is the implicit assumption that individuals have the capacity to participate in terms of accessing the forums, access to information and knowledge to make informed arguments, competency for raising their arguments, and an enabling environment in which the debate can be held. Giddens' Structuration Theory [Giddens, 1984] shows how structures of communication and language are also influenced by power and sanction. Thus in using communication and rational debate as the *modus operandi* of realising democracy there is the need to investigate explicitly how these structures are formed. Structures are located in the minds of human actors, not in external constructions. Through the public debate and action, capacities, assumptions and beliefs change and so does structure itself. Capacity to communicate is an underlying implicit assumptions for rational debate to take place and to affect the process of structuration.

Thirdly, Habermas comments that a discourse-centred concept of democracy demands that all parties that might be affected must be included; that they can interact in a free, equal and easy manner; that there be no restrictions on topics; and that the outcomes can be revised.

In the public sphere of the 17th and 18th centuries, the coffee house convention was that all had the right to speak, that all had the responsibility to listen to others, and that people should respond critically to what was said. If participants disagreed, the discussion should continue until the issue was resolved. The idea was that if the debate continued in this manner, prejudices and incorrect information would be unearthed. This would allow the better, more rational argument to emerge victorious. Habermas describes a normative model that is associated with

a specific set of class and general interests and is inaccessible to most citizens [McLaughlin quoted in [Thornton, 2001, p. 14]].

Though Habermas argues for all individuals to have an equal say in the discursive process his idealised public sphere is based on an exclusive social setting - the debate in the coffee houses being the prerogative of white male property owners.

It is interesting to note, as other authors have done [Kellner, 2004]; [Thornton, 2001], that the focus on the coffee houses was at a time when other significant public discussion forums of the excluded were in existence and conflicted with the mainstream debates, such as the women's and civil rights movements . As Ryan notes [Ryan, 1993] it wasn't just that Habermas neglected women's public spheres, but also that he marks the decline of the public sphere at the precise moment when women were beginning to get political power. The exclusion of certain people from the debate determines not just what is included in the debate, but also what is excluded and the process of the discussions itself. On the latter, for example, says Fraser, men interrupt women more than women interrupt men, men speak more than women, and when women do interrupt they are ignored more than men [Thornton, 2001, p. 17].

Fraser posits the existence of a number of smaller public spheres rather than one large comprehensive sphere. (Fraser calls these groups 'subaltern counter publics' [Fraser, 1993, p. 123].) The discourse would cover all the items affecting that particular group and nothing would be excluded from consideration. In this way, it may be possible for subordinate groups to convince dominant groups that their concerns are legitimate. Habermas does, however, state that public opinion isn't formed and articulated in one particular forum. Fraser distinguishes between 'weak-publics' and 'strong-publics' in Habermas's public sphere. 'Weak-publics' are fora within civil society for the formation of opinions, but not for decision taking, for example residential community associations. 'Strong-publics' encompass both opinion formation and decision making, for example parliament. [Fraser, 1993, p. 134/5]

For Habermas' public sphere to emerge there is a need for participants to have unlimited access to information and equal participation in cultural discourse. Increased information affords citizens the opportunity to make better arguments and to engage in the debates that affect them on an equal footing. Access to information implies access at a local level and the mutual understanding of all participants at that level. With respect to different forums for discussion, face-to-face communica-

tion and argument in clarifying divergent meanings and the need to arrive, through a participatory process, at a common understanding are thus important. This extends beyond using the same language, but also in explaining the meanings, signs and symbols in common usage.

Public opinion can only be formed if the public engages in rational discussion. Although Habermas believed that the coffee house scenario possessed the potential to develop into the public sphere, the sphere was invaded by the State and the media. Habermas argues that over time corporate interests colonised the sphere of the mass media, and that major powers in society such as the market, the state and organisations took over the public sphere. So rather than the public sphere being a sphere of communicative rationality, it became a forum of instrumental rationality. Motivated by these concerns, Habermas argues that as the public sphere expands, the quality of discourse declines [Calhoun, 1992, 3].

In Habermas's conception of the public sphere, it is operating in favour of 'the common good'. This assumes that:

- there is one undifferentiated public for whom a common good is possible;
- there is only one public arena that works for everyone, and;
- this is a desirable state of affairs.

Subordinate groups must assume the discourse of the dominant group before they can participate in a debate, and this may include disregarding what to them are crucial issues. This is amplified if there is one comprehensive public sphere. [Thornton, 2001, p. 23]

However, Habermas believed that striving for an 'Ideal Speech Situation' could address the problem of instrumental rationality. The conditions for the creation of an 'Ideal Speech Situation' may be summarised as:

- the extent of access (as close to universal as possible);
- the degree of autonomy (the citizens must be free of coercion and be allowed to question and introduce any assertion);
- the rejection of hierarchy (each person should participate and express her or his attitudes, desires and needs, on an equal footing);
- the rule of law (particularly the subordination of the state), and;

- and the quality of participation (the common commitment to the ways of logic as well as the competence to speak). (Adapted from Rutherford 18 [Bass, 2004]).

In this case study some of the debate around attaining the 'Ideal Speech Situation' was useful. This included:

- an emphasis on the importance of communication in the process of structuration;
- that communication implies understanding meanings and interpretations, and goes beyond the use of language, and;
- the criteria for attaining an 'Ideal Speech Situation' can help heighten awareness regarding the development of forums for open and free debate, and can be used to evaluate the creation of such spaces in IS design.

There are, however, two very important differences in the way in which these criteria are applied in this case study. The focus of Habermas regarding the creation of the public sphere and his conceptualisation of democracy is very western. In this case study the collective community decision-making and action of the community in the UThukela District is in contrast to Habermas' coffee shops where the rising bourgeoisie debated issues of life. Additionally, rather than aiming for one public sphere, a number of sub-spheres were created to more effectively apply the principles of the creation of the Habermasian public sphere.

9.3 Communication in the process of designing a CBIS

In this section I look at how an enabling environment for public debate was facilitated through the creation of a common vision and through exploring the understanding of local terms for childhood illnesses. Next I explain how social processes which affect communication and language were taken into account in the development, design and implementation of the system.

9.3.1 Creation of shared vision

As already mentioned the approach to develop a client focused health service in OKhahlamba Municipality represented a paradigm shift from the earlier focus on

curative health centre based service delivery. With the national change to a PHC approach adopted after 1994 in South Africa the new focus is on prevention, clients and quality. In addition the child-health intervention within TDCSP, along with the District Health Management Team, adopted a future focused approach to planning for child-health based on the co-determined vision: *to achieve optimal health, growth, development and well-being of children within the family and community in the UThukela Health District.*

The implications of the vision for IS was the focus on measuring children's health in a holistic way and describing its status with respect to the attainment of the vision. So instead of saying 80% of children are immunised, we would say that we still need to immunise 20% of children. This approach reflects what is required to be done to attain the vision and thus, hopefully, stimulate action. Adopting a forward looking perspective also stresses the importance of monitoring the present context and measuring changes in that context. Action plans on how to achieve this vision were then developed. This was a move away from the more common position of reacting to situations, i.e. reacting to health associated problems and externally initiated requests.

In the February 2000 workshop, discussed in Section 6.2.2, the existing routine HIS and the periodic surveys held were examined in relation to measuring progress towards this vision. The existing HIS was viewed as inadequate and the recommendations arising from that meeting included the need to:

- negotiate local measures of success;
- share information on monitoring and evaluation, and;
- arrange another meeting.

It was these recommendations that provided the impetus to work on a child-health CBIS.

9.3.2 Local meanings for childhood illnesses

Before commencing on the development of local level indicators it was important to create a common ground for discussion of child-health. Reflection on the situation of children was needed to develop a clearer understanding of common childhood illnesses from the perspective of all parties involved in the health status of the child. Through participative work conducted by TDCSP staff in the initial stages of the

Project, research on the local understanding of childhood illnesses was conducted. The example of how diarrhoea was understood and treated is given here. All other common illnesses affecting children were investigated in a similar manner [Gibson et al., 2000].

Information concerning the care of children with diarrhoea was collected in FGD's and through critical incidence analysis (where mothers were asked to relate the steps they took to deal with the diarrhoea from the time the child first became ill). Six mothers of children who had recently had diarrhoea were interviewed at the health facilities and 4 mothers who were in hospital with their children took part in the critical incidence analysis research (total of 10 mothers). Diarrhoea was perceived to be the most common childhood illness by the participants and there was agreement that this illness is caused by unhygienic conditions associated with child and animal faeces, lack of sanitation and unprotected springs resulting in unclean water. There were also some local traditional beliefs which needed to be taken into account, as these traditional beliefs shape perceptions of both causes and treatment of diarrhoea.

The majority of mothers and grandmothers say that "a child who suffers from diarrhoea has *inyoni*" (literal meaning of *inyoni* is bird). This happens when a mother has been in contact with lightning strikes and evil spirits are then inhaled which causes diarrhoea in the child. *Inyoni* is also associated with eating mushrooms when the woman is still pregnant (mushrooms grow following a thunderstorm). The signs and symptoms of *inyoni* are dehydration, sunken fontanel, green stools with, in some cases, mucus in the stool. It may also be associated with thrush and teething.

Most mothers and grandmothers say *inyoni* has to be treated by a traditional healer who will administer an enema and give the child *imbiza* (herb mixture) to drink. The child may be 'scarified' as well. Treatment often takes place where the lightning struck and it is important not to look back once the *inyoni* has been removed otherwise it will follow and attack the child again. There is a difference between children with big *inyoni* and small *inyoni*. It was generally accepted, though particularly by grandmothers, that if big *inyoni* is not removed the child will continue to be sick, thin and unhealthy and may even die. Some mothers said they did not consult traditional healers because the strong medicine they use may kill the child and the medicine does not give energy. One grandmother, on seeing a

desperately ill child in hospital and being told it was the result of taking out *inyoni*, decided she would never take out *inyoni* again.

Most other important child-rearing practices that are believed to contribute to the well-being of the child under five were investigated in a similar manner. Some of the traditional beliefs and practices were easier to incorporate than others into the standard methods promoted by the health facilities. For example, with breastfeeding, when a mother has been separated from her child while she is breastfeeding, should she wish to continue when she returns, she needs to express the milk in her breasts first. There was general agreement about this, though some mothers express milk outside the gate of the home and others onto a hot hoe. Reasons for this were given as:

- If the breasts are too full the baby may be choked by the milk.
- Expressing prevents the child from getting evil spirits (*habula*) which could cause illness and even death.
- If one continues breast feeding without expressing, the child will develop stomach pains and the child will die.

In a subsequent FGD one elderly gentleman suggested that if the mothers just expressed 'one tot' from each breast, then the mothers would still have sufficient breastmilk for their babies and will still be in keeping with local beliefs and practices. As such traditional practices and recommended practices of the health practitioners could be meaningfully combined into a healthy practice for the child.

In the case of diarrhoea, giving an enema to an already dehydrated child is very dangerous and cannot conceivably be integrated into the current practice advised by the health workers of rehydration (using a sugar salt solution or other appropriate home fluids). The belief of *inyoni* is very strong. As a compromise, it is possible that the health practitioners could persuade the mother or grandmother that the child needs to be re-hydrated first. When the child is strong, then the child can fight the *inyoni* better and at this stage an enema can be given if necessary. The hope would be that the care-givers will not administer an enema to a healthy child in the belief that the child has already got rid of the *inyoni*. This issue has not as yet been resolved.

Understanding local practices and developing a dictionary of common terms used for childhood illnesses allowed health practitioners and carers of children to discuss child-health using common terms [Gibson et al., 2000]. This also helped in defining

data items later on when the data collection tools and the prioritisation of indicators were being discussed. It also allowed health facility staff to understand why certain practices occurred and why advice from health facility staff was sometimes not followed. This was an interesting process as most of the health facility staff were from the same geographical area and shared a similar traditional background. It further allows people with divergent beliefs to interpret other people meaning in data collected or in information shared.

... interpretation is central to the process of IS design, implementation, and use. Material agency influences, but does not determine, the opportunity space for these interpretations. Rather, interpretations depend on emergent, situated social/social social/technical interactions, which will be influenced by preceding context. Since the context and conditions for action will vary between individuals, interpretations are also idiosyncratic. [Jones, 1998, p. 298]

9.3.3 Connecting with broader networks

Once we had a better understanding of local child rearing practices and health-seeking behaviour, the next step was to develop an IS that would allow communities to monitor the health of their children. Part of this was the process of developing local level indicators. As mentioned in Chapter 6, Section 6.2.4, during the process of developing the child-health CBIS, community members felt that they were not looking for an absolute value to be placed on childhood vulnerability or risk. Rather there was the need to track changes in this status and to know when action needed to be taken. Often in IS design too much time is spent on defining indicators and not enough time is spent investigating and understanding its meanings and interpretations. As a result, many of the questions or prompts on the household observation form which is used by Community Health Workers, cannot be objectively measured. For example, the questions on whether the household is loving or whether the child appears happy are subjective. The Community Health Workers feel that the prompts alert them to potential 'at-risk' situations and they will investigate or visit that household more often based on this impression. Based on their experience and instinct they are confident that they would be able to 'pick-up' a child living in a risky situation and would monitor that household more intently than others.

Given the complexity of the health system, some of the indicators chosen were standardised with the already existing indicators within the health facility IS. The indicators that are sent to the District Information Officer include total births at home, number of child deaths, children not immunised, number of children referred and growth indicators (faltering, gained and lost weight). Standardisation of systems and meanings is important and hence the data definitions for these indicators are common between the health facility staff and Community Health Workers.

In our research, the CBIS comprised locally developed indicators which had specialised and context specific meanings and standardised data items for transmission upwards in the health system. In order to have their voices heard, community members needed to also have access to data from other sources. Enabling forums for discussion of the data collected were enhanced. New technology was not introduced at community level as this was not a realistic option given the lack of electricity, technical skills and financial resources. More importantly, community members felt that if the information flows and communication channels were addressed they would be able to solve most of their problems and address the challenges facing them without any new technology.

9.3.4 Communication and social processes

The structuration process, as outlined in Chapter 2, Section 2.2.1, described the link between communication, power and sanction. The language used to communicate is influenced by power and what is viewed as legitimate or what is sanctioned socially and culturally. For example, the language used to express a childhood illness reflects the traditional customs and values and is respectful of spiritual and traditional forces of power. Traditional customs and transformation of the health system were important in understanding the context and shaped the IS design.

Strong Zulu cultural and traditional values exist in the OKhahlamba Municipality (Chapter 5.3, Section 5). Traditional leaders are highly respected. Grandmothers and traditional healers are often the first persons to be consulted in times of illness and many locally available remedies and treatments are used and practised. In the initial stages of the child-health intervention the traditional forms of collective decision making were not only respected, but used to influence the design of the IS. Traditionally, decisions that affect the community at large are taken collectively through community meetings (*imbizo's*). Child-care is not the responsibility of a

sole care-giver but involves a network of family members. Child-health is viewed holistically and as the responsibility of the community.

The unequal nature of social relationships and positions between different actors and also institutions was recognised from the outset. In addressing this the various forums, as described in Chapter 7, Section 7.4, were established. Capacity to reflect on the data and to learn from the data was also developed. In terms of capacity to act, or to make decisions, most respondents, in the research undertaken, felt that they could act if given appropriate information and if key role players were included in the communication loop with one another. The visioning exercise started a communication process, but this needed to be developed into more formal communication structures. In keeping with traditional forms of communication, face-to-face communication was largely relied upon. The use of song, dance and poetry was also encouraged.

9.4 Criteria of Ideal Speech Situation revisited

Before concluding this chapter on the analysis of communication in the process of design and implementing of the CBIS I return to the the criteria given above for the 'Ideal Speech Situation'. After all the 'Ideal Speech Situation' is ideal and cannot, therefore, be attained.

9.4.1 Extent of access

Some of the issues relating to access were addressed by the facilitation of the meetings in the local language, isiZulu. The interviews and discussions were conducted as close as possible to the work or living environments of the participants. Existing mediators were relied upon for conducting the interviews and facilitating the discussions, so that, if there were any issues raised that needed continued support and assistance, the exiting structures could be relied upon to take these issues forward. Participatory techniques were used, such as mapping, critical incidence analysis and other PLA methods in the community meetings and discussions. As the design and implementation of IS is often viewed with great trepidation and doubt, training was conducted in data collection and analysis techniques. Community members were heavily involved in the various TDCSP evaluations and research. Feedback of any surveys or research conducted through the Project was relayed back through

community meetings and written reports. Time frames had to be flexible to fit in with a busy community life. Harvest time, the weather and community celebrations had to be taken into account in the design and implementation process.

Not all community members were included in the research. As indicated in Chapter 4, Section 4.3.3 the total number of participants was 103² and the predominant focus was in the OKhahlamba Municipality. Women are subject to 'time-poverty'. This means that many of the women, who possibly could hold very different views and perceptions to those who did participate, could have been excluded in the research. Announcement of the meetings and discussions was conducted via word-of-mouth and therefore, if community members were not part of these communication loops, they would not have known about the meetings. In a relatively small community this was not perceived to be a big problem.

9.4.2 Degree of autonomy

There was no obligation placed on members of the community to participate and their confidentiality was ensured. The research team made an effort to provide forums for the airing of different views, whether in mixed group sessions or in groups arranged by gender or age, such as teenage mothers.

Within the FGD with the children, two of the children, when asked about whether they felt they were vulnerable or 'at-risk', indicated that they felt they were. However, they did not feel like talking about it at that particular time. The further discussion, and the assistance the children required, would be provided at a later stage. As the group's 'mother' (group leader) had conducted the FGD she would be able to investigate this further during the regular meetings of the group. This shows the importance of trying to link the research with existing structures and systems, so that any issues that arose that could not be discussed in that meeting could be postponed and addressed in a later meeting. There may have been social pressures to participate, or not, placed on individuals which we, as the research team, were unaware of.

²There are no figures for the 4 FGD's in ENdaka and EMtshezi Municipalities and the 1 meeting with facility staff also in the EMtshezi Municipality.

9.4.3 Rejection of hierarchy

Given the participatory nature of the discussions and the number of different techniques that were used throughout the implementation of the complete child-health intervention (such as meetings, interviews, PLA sessions, group and individual discussions and feedback sessions, village health days, presentations and written reports) attempts were made to get a genuine reflection of different viewpoints and suggestions. However, the Project can influence, but cannot change, how authority plays out in the community. So even though different viewpoints have been elicited in the research sessions and opportunities have been created in the establishment of different forums for communication, these forums cannot be the sole conduit for changing social inequalities and hierarchical structures within that society. They can assist.

9.4.4 Rule of law

Fortunately, there is the recognised obligation by the State to fulfil the rights of the child to good health. There is also legislation which encourages, and also obligates, the duty bearers to realise the right of the community to participate in local governance structures, for example the obligation of local government to ensure the setting up of Community Health Committees. Prior to 1994 the government was run in a very top-down fashion and changes to a more participatory style of governing takes time to be realised. Traditionally there has always been community involvement in decision-making, though this gave preferential treatment to men.

The lack of knowledge of rights and entitlements by members of the community may mean that they do not demand that their rights be realised. For example, though each child has the right to education, frequently children are not attending school due to inability to pay school fess or because the children do not have a school uniform. More education and increasing awareness of parents, children and other rights holders, as well as those obligated to realise these rights, is needed.

9.4.5 Quality of participation

In this research different forums for discussion were organised before bringing the divergent parties, for example mothers, community leaders, district health staff, health facility staff and academics, together. Thus 'sub-spheres' were created to fa-

facilitate participation and greater debate, rather than attempting to create one large sphere. The same principles for free participation, in terms of access, autonomy, rejection of hierarchy, rule of law and the quality of participation, would still apply to each of these spheres.

Given the long history of the Project there are good relations between Project staff and the community. Within the interviews, meetings and discussions at community level or at district level good participation was reported by the facilitators. No perceptible differences between men and women or between those in authority and those not was apparent. This may be due to the capacity development of the people conducting the research as they have had extensive training and experience in data collection and analysis techniques during the duration of the Project. Community members are accustomed to being requested to participate in research activities, as there has been quite extensive consultation between the community and the Project staff. Regular feedback on the results of any research conducted by the Project staff occurred. On the negative side, participants may respond in a way they believe a researcher expects them to. Though the research team were aware of this possibility, it is difficult to perceive whether this occurred in reality.

An important issue faced was when we had a combined meeting with representatives of the community, Project and district staff on the determination of the indicators based on the complete data collected. The people associated with the community (representatives of the Community Health Forum and the supervisors and personnel of the community-based programmes) were very quiet in offering suggestions on how the data could be collected and how best to define the indicators. Interestingly, though there was much discussion by the other members not much progress was made in determining the community-based indicators. Progress was made in a subsequent meeting with the Community Health Workers and Community Health Supervisors. A combination of isiZulu and English was used in both meetings and there was no significant difference between the participation of participants who were employed by the Project or the District Department of Health and the participants who were volunteers. I facilitated both meetings in the same venue. I can therefore assume that it was not the content of the discussion that was difficult, but the combination of the different hierarchies in the group. There is obviously a greater need for making these combined meetings more conducive to participation by all members.

9.5 Conclusion

In the design and development of IS the case study illustrates the importance of facilitating an enabling environment or common ground for dialogue through the development of a codetermined vision and through sharing meaning and understanding of the terms used. The criteria for the attainment of the 'Ideal Speech Situation' provided a useful framework in which cognisance was taken of the criteria in developing forums for communication, as well as in the analysis of the process followed. Striving for the attainment of the 'Ideal Speech Situation' helped the research team and participants to :

- highlight and sensitise issues of power;
- build on existing structures and systems;
- develop capacity and the accessibility of participation, and;
- understand the important role of communication and sharing our meanings in IS design and development.

But clearly the 'Ideal Speech Situation' was not achieved. Table 9.1 summarises the positive influences in attaining these criteria and also the potential distortions. It provides a useful framework in which communication in IS design can be highlighted and evaluated.

Criteria	Positive influences	Potential distortions
Access: (close to universal)	Local language used Close to home or work Known facilitator or mediator Participatory techniques employed Flexible approach	'Time-poverty' of women Used existing structures with existing constraints
Autonomy: (free of coercion, allowed to question, and can introduce any assertion)	Not obligatory to participate	Social pressures and tradition Could say what they feel facilitator wants
Hierarchy (ability to participate, and free to express attitudes, desires and needs)	Good participation in smaller groups Use of participatory techniques	Poor participation in mixed groups Influence of social inequalities and hierarchical structures
Rule of law (especially lower levels government)	Participation endorsed in legislation Traditional communal decision-making	History of non-participatory government Insufficient knowledge of, or capabilities to demand for, rights
Quality (common commitment to the ways of logic, and the competence to speak)	Long history of TDCSP Capacity of facilitators and community members developed	Less participation in larger groups

Table 9.1: Criteria, positive influences and potential distortions in striving for the 'Ideal Speech Situation'

Chapter 10

Theoretical contributions

This chapter explores the theoretical contributions this research has made by returning to the theories which shaped and informed the research as outlined in Chapter 2. The main contributions are in extending the social theories I commenced with - Structuration Theory and Critical Social Theory. I further contribute to IS research through the design of a CBIS, extending the debate on participation to non-western contexts and going beyond formal communication. I engage with the contemporary debates on scale and sustainability, the use of action research and on generalising from qualitative research. This chapter therefore addresses the research question **What are the theoretical implications of the experiences gained from the case study?**

10.1 Introduction

In revisiting our action research model, there are two important contributions of using such an approach to address a problem. One contribution is that action is taken to change the immediate situation and the problem at hand. The other contribution is through the development of theoretical and practical generalisations. This chapter focuses on the theoretical generalisations.

I commence with how my research has extended Giddens' Structuration Theory in terms of its application to a South African case study, how I used it empirically and how I incorporated Critical Social Theory into it. The gap of CBIS in contemporary IS research is also addressed. This includes a discussion on the meaning of community and how to integrate a CBIS with a facility HIS. This research has extended the debate on participation to non-western contexts and goes beyond the formal view of communication often taken in IS research. Further contributions are made to the debate on sustainability and scalability, the methodological approach taken to action research and the debate on the making of generalisations from a single qualitative case setting. Each of these theoretical contributions is elaborated in more detail in the following sections.

10.2 Extending Giddens' Structuration Theory

Structuration Theory has been criticised for not being empirically relevant. In this research, I counteract this criticism by arguing that Structuration Theory offers a conceptual approach to IS design. This theory assists in taking a multi-levelled approach to the social context in which IS is designed - a gap which needs to be addressed. Structuration Theory was used empirically in exploring a community setting in South Africa. Critical Social Theory was used to further explore issues of power and communication in the structuration process. Each of these elements offers an extension of Giddens' Structuration Theory and is discussed below.

10.2.1 South African Context

The more usual applications of Structuration Theory are in organisational settings, though there are a few examples of this theory being used outside the workplace in IS research ([Sahay and Walsham, 1996];[Kanungo, 2004]). Using Structuration

Theory in a rural context provided a way in which the environment could be explored more broadly, especially within a context that needs a multi-levelled and multi-sectoral analysis. Traditional approaches in IS research tend to treat levels rather separately in IS design [Walsham, 1993, p. 246]. Structuration Theory can be used, as illustrated here, to emphasise the way in which the various levels, in terms of individual, group, organisational and societal, are inextricably interlinked and constituted by each other, as the structuration process takes place simultaneously and interacts on many different levels.

10.2.2 Empirical use of theory

Structuration Theory is criticised for lacking methodological context, that there are no concrete ways given of how to proceed in acquiring the knowledge needed to understand the structuring process [Gregson, 1989]. However, this case study shows that the modalities of structure are useful in understanding the context in which IS is to be designed. This empirical approach is in line with Giddens' own suggestion to researchers - to use aspects of Structuration Theory rather than attempting to apply the whole thing.

Structuration theory is not intended as a method of research, or even as a methodological approach. ...the framework of structuration theory provides concepts relevant to empirical research and also warns against the pitfalls of some types of research procedures or interpretations of research results. [Giddens, 1989, p. 296]

Through the analysis of the modalities within the dimensions of structuration, issues of power, communication, and sanction were emphasised in the emerging opportunities and challenges. The importance of power and political action has received significant attention in the IS literature (see [Walsham, 1993] for summaries of examples in IS literature). However, the processes of the exercise of power, and the taking of political action, is highly complex, both in theoretical terms and in attempting to observe it in practice. To adequately explore power would require a longitudinal study, with the associated constraints of time and resources. Furthermore, it is difficult to produce good 'prescriptions' in the complex area of political action [Walsham, 1993, p. 41]. Power is complex and important, and should command significant attention in IS design. Power is instantiated in action

and is not a resource or act [Giddens, 1984]. In this case study, participation and the development of communication loops and forums were used to address and highlight these power imbalances.

Giddens reminds us that power is not necessarily a bad thing - it is the capacity to achieve outcomes [Giddens, 1984, p. 257]. An argument against Structuration Theory's claim that all action contain the seeds of change, is the claim that Structuration Theory doesn't adequately take into consideration the differences in the constraining structures which affect different groups of people, such as women living under repressive regimes or peasant labourers. Such groups, compared to many others, have very little power and ability to change their situation and it is argued that Structuration Theory doesn't take this into account [Jones, 1997].

Changing the IS is a necessary, but not a sufficient, condition in changing structures of power and domination. There is also the need for commitment and support from the government and society for structural changes to be made. Information associated with the use and development of IS, can be regarded as knowledge for social action [Lyytinen and Klein, 1985]. This information can assist in an improved knowledge base which can be used to put pressure on government and civil society to change the restrictive structures in which people live. Structuration Theory enables a researcher to understand the causes of the enabling, as well as, the constraining structures of power. It is also important to look and explore how participation in the design process can assist with making power an enabling, rather than restrictive, source of interaction for the marginalised, in the structuration process.

Structuration Theory assists in this research with the choice of the philosophical assumptions made in the empirical research. The model used in Section 4.3.2 of this thesis illustrates the breakdown of IS research traditions into the three broad philosophical approaches - positivist, interpretivist and critical. The research approach adopted here is a mixture of interpretive and critical. Structuration Theory facilitates the adoption of this mixed approach. As Walsham argues, there is the need to adopt theories, namely constitutive process theories such as Structuration Theory, in IS research in an attempt to dissolve the boundaries between such traditions “.. in emphasising not only the importance of subjective meaning for the individual actor, but also the social structures which condition and enable such meanings and are constituted by them.” [Walsham, 1993, p. 246]

10.2.3 Integration of Critical Social Theory

The integration of Critical Social Theory within Structuration Theory illustrates the value of Structuration Theory as a meta-theory. Critical Social Theorists acknowledge the imbalances in power from the outset. In particular, striving for the Habermasian notion of the 'Ideal Speech Situation' requires an investigation into the principles of setting up a public sphere. Issues of access, autonomy, hierarchy, rule of law and quality of the forums are exposed as important issues in IS design.

The use of Habermas' theory of communicative action, and striving for the public sphere, also has implications for the role of the IS actor in society [Walsham, 1993, p. 237/8]. The categorisation of the role of the IS actor can be directly related to Habermas' concept of knowledge interests - technical, practical and emancipatory [MacIssac, 1996] [Ngwenyama, 1991] [Lyytinen and Klein, 1985]. Many of the traditional approaches to IS design view the IS actor as solely a technical expert. This research shows that IS design goes beyond technical functionality of a system, though these skills are needed. There is the need to gain understanding, to engage in dialogue and enhance participation. This constitutes a practical view of the IS actor - a view of the IS actor as an enactor of meaning for the attainment of stability based on discourse. However, it is the third role of an IS actor as a moral agent that is highlighted in this research. Through this role power relations are revealed and critiqued. An IS actor cannot avoid ethical issues when designing an IS, especially in health, and ethical positions are adopted whether they are made explicit or not. What is ethically and morally sanctioned, or what behaviour is considered legitimate, reflects the reflexive and recursive actions and interactions of people.

As health status can also be used as an indicator of human development and freedom [Sen, 1999], the potential for the HIS as an advocacy tool extends beyond the health facility. Access to ICT's has the potential of linking the PHC sector to global flows of information and knowledge, to enable their voices to be heard and as such improve their position in the health system. Improved information infrastructure in these marginalised communities can lead to better health services because of increased transparency as well as increased opportunity for political and social pressure [Mosse and Byrne, 2004]. Sen makes the case [Sen, 1999, p. 44] for a strong relationship between public expenditure on health care and poverty and argues strongly for an informational basis for this connection. In this way HIS implementation can also be a tool for human development and freedom and the IS

actor a moral agent. If IS designers adopt an approach to IS design that improves the human condition and development workers also approach IS as a necessary, though not sufficient, factor for development, then IS design can contribute significantly to human development.

10.3 Design of CBIS

10.3.1 CBIS inadequately addressed in IS

There has recently been debates over the involvement of community members who will be served by the health system [Braa, 1996] [Korpela et al., 1998]. This argument is based more on an intuitive basis, rather than on empirical grounds. This research addresses the absence of the design and development of CBIS from mainstream IS research.

From my review of documents related to health and community development, the literature on sustainable livelihoods approaches was the most useful for developing a CBIS. Community-based monitoring is an integral component of the sustainable livelihoods principles for livelihoods monitoring and evaluation. Specifically the work of Guijt offers some useful insights into monitoring and evaluation from an empowerment perspective [Guijt, 1998]; [Guijt et al., 1998]; [Guijt and Cornwall, 1995]. Abbot and Guijt [Abbot and Guijt, 1998] describe monitoring approaches that develop partnerships of multiple stakeholders for efficient, effective and socially inclusive monitoring in the context of tracking environmental change in general, and of projects focusing on environmental regeneration. Guijt [Guijt, 1998] explores the concepts of participatory monitoring and evaluations and develops some generic steps undertaken in adopting such an approach.

The implications of the sustainable livelihoods principles for livelihoods monitoring and evaluation are similar to the implications of adopting a human rights approach to a participatory monitoring and evaluation system [Pasteur, 2001]. Table 10.1 looks at the similarities.

However, adopting a human rights approach entails a different normative stance to sustainable livelihoods. From a human rights perspective the inclusion of the community into the HIS is obligatory. In South Africa this is a legal obligation, but for IS researchers it is also a moral obligation.

Principles of Sustainable Livelihoods	Implications of human rights:
People-centred and participatory	Obligation to involve community and participation as a political process
Holistic and cross sectoral	Multi sectoral
Linking micro to macro	Multi Level
Dynamic and sustainable	Flexibility through participation
Support a 'learning approach process	Capacity development and adopting a learning approach

Table 10.1: Monitoring and Evaluation: Human rights implications compared to sustainable livelihoods principles

10.3.2 Understanding of community

Much of the literature on organisational culture suggests that there is a single organisational culture [Walsham, 1993]. Such an approach ignores the existence of subgroups and that multiple meanings can be attached to the same events. Within IS there is little work that addresses the issue of subcultures within organisations and the few exceptions normally contain no analysis of the processes of maintenance and change of subcultures [Walsham, 1993, p. 37]. This is similar to the way in which 'community' is viewed in development studies and literature.

Despite the stated intentions of social inclusion, it has become clear that many participatory development initiatives do not deal well with the complexity of community differences, including age, economic, religious, caste, ethnic and, in particular gender. Looking back, it is apparent that 'community' has often been viewed naively, or in practice dealt with, as a harmonious and internally equitable collective. [Guijt and Shah, 2001, p. 1]

The internal dynamics and differences are inadequately understood.

This mythical notion of community cohesion continues to permeate much participatory work, hiding a bias that favours the opinions and priorities of those with more power and the ability to voice themselves publicly. [Guijt and Shah, 2001, p. 1]

In participatory approaches there is often the wrong assumption of a static picture: that differences are simplified in terms of 'insider and outsider'; normative assumptions are taken that presupposes participation moves from coercion to autonomy,

and the higher participation is on the 'ladder' to autonomy the better. All of these typologies ignore the diversity of participation which can take place within each of the levels or groups [Guijt and Shah, 2001, p. 10]. A common error in community development projects is to view communities as a homogenous whole, bereft of differences which occur at all levels of society [Puri, 2003, p. 32/33].

A criticism of the process of structuration is that it doesn't help explain why some forms of social reproduction succeed and become institutionalised and others do not. An explanation to this criticism can be found through understanding 'sub-groups' and 'sub-cultures' and how different 'sub-groups' can react differently to the same situation. Orlikowski and Robey, quoting Heyderbrand, note that even if agents are knowledgeable, it does not necessarily mean that they will change structures which oppress them.

Merely being capable of changing structural properties does not imply that those capabilities will be exercised, and while human actors always have some capacity for independent action, there are no guarantees that such resources will be drawn on. [Orlikowski and Robey, 1991, p. 150]

Along similar lines to this argument, is the criticism of Habermas' approach that emancipation is desirable to all. There might be psychological, as well as social costs, to this emancipation. Human actors may prefer to leave the situation unchanged, and not take action, even if they believe that this could improve their life condition. However, the point in this research, is not for the researcher to strive for the emancipation of the individual, but to create an enabling environment for reflection and learning and the development of capacities and capabilities, so that once these has been achieved the possibility for change exists. Within one group, not all its constituent 'sub-groups' will necessarily act in the same fashion.

10.3.3 Integration of systems

Within this research there were a number of practical difficulties with the integration of the data from the CBIS with that of the HIS. These difficulties included:

- A large number of Community Health Workers have been employed within the district in the last two years. The training curriculum of the new Community Health Workers is very broad and includes all aspects of community development. Whilst this forms a broad base from which to work, training on how to

prioritise within the area in which the Community Health Worker is working has not been done. Most of the community-based personnel do not have a clear vision of what their role is and what their priorities are. Designing an IS without a clear vision on what is to be achieved is impossible.

- Only the Community Health Workers from the OKhahlamba Municipality have received training in IS. The other Community Health Workers have not.
- The area for which the Community Health Workers are responsible (the catchment area) does not coincide with the catchment areas for the health facilities. It is difficult to match the data collected by a Community Health Worker with the data from a given health facility as the geographic areas are not coterminous. The District Information Officer has agreed to include, in the district information reports produced, the data from the Community Health Workers in the OKhahlamba Municipality aggregated to the municipal level.

Chilundu and Aanestad [Chilundu and Aanestad, forthcoming] note that the fundamental reason for difficulty in integrating IS are the differences in the rationalities of the developers of the systems. Given that there were very different role players involved in the design of the CBIS and the HIS, that the development took place at different times and that the IS is to serve different purposes, it is not surprising that there were difficulties integrating the CBIS and the existing HIS. These difficulties include technical aspects, for example the areas not coinciding, as well as the broader issue of the purpose of the IS with respect to the perceived role of the Community Health Workers. The lack of a clear Community Health Workers Policy in the province, and nationally, creates the difficulty of effectively embedding the child-health CBIS into the DHIS. These are issues currently being addressed by the District Information Officer in the UThukela District. The approach taken in this case study was to incrementally integrate community-based data into the facility IS. This is in line with the approach, described below, of Braa and Hedberg [Braa and Hedberg, 2002].

In a study of the history of the International Classification of Diseases, Bowker and Star write: "There is a permanent tension between attempts at universal standardisation of lists, and the local circumstances of those using them; . . . this tension should not, and cannot, be resolved by imposed standardisation, because the problem is recursive." (quoted in [Braa and Hedberg, 2002, p. 115])

The term used by Braa and Hedberg, 'cultivation', is perhaps more apt within IS design, where 'cultivation' is the

...slow, incremental, bottom-up process of aligning actors by enabling translation of their interests and gradually transforming social structures and information infrastructures where the resources already available form the base. The precise outcome of the design process is not given, but is negotiated within a broader set of goals. [Braa and Hedberg, 2002, p. 119]

Due recognition of the tensions between standardisation and localisation is also given where

...local freedom to define their own information needs is granted and the number of standardised data items, which are what the conflicts are about, are kept as low as possible. Within this framework, standards are seen as interfaces and gateways for communication between relatively independent actors (i.e. modules) across organisational structures and hierarchies. [Braa and Hedberg, 2002, p. 119]

10.4 Extending debate on participation to non-western context

PD has been a topic of keen debate in the IS literature and participation has been used as a strategy in which to address power. However, much of the research and debates have been confined to western contexts, with only limited and peripheral contact with developing country settings. Although some evidence of the attempts to extend IS research to 'developing country' domains has recently become discernible in the mainstream IS literature (for example, [Walsham, 2003],[Sahay and Avgerou, 2002]), the issue of PD in these settings has lacked specific attention. Furthermore, there are very few examples of the PD of IS outside of the work context, even in western contexts. When related to community development programs the argument for participation is based on a more intuitive and ethical basis, rather than on empirical grounds. What is important in participation in IS is: who decides what data to collect; who collects it; who interprets the information and uses the findings, and how participation can make decision-making a more democratic

process. Participation in IS design should be a social process of bringing people together to understand different views and share decision-making.

The case study presented in this thesis shows that participation needs to be more clearly defined in IS research. Given that PD is contextual, practical examples of how and why participation took place are needed. The analysis of participation, in this case study, indicated the need to move away from the workplace to the community served by the PHC services; from participation of workers for improved design to participation as a right; from a vertical health system to a more multi layered and multi sectoral approach, and; from skill enhancement in system design to capacity development which facilitates participation and that addresses the challenges faced within systems and structures of health and related sectors.

An analysis of three case studies implementing HIS in three different developing countries (Mozambique, India and the case study presented in this research), reveals that the politics of design, the nature of participation, and the methods, tools and techniques for carrying out design projects, are shaped by the diversity of the socio-economic, cultural and political situations faced in each of these settings. Though common strategies, such as capacity development, could be found that cut across the three case studies, it is the importance of the contextual nature of PD that emerges most strongly. There is no single algorithmic best practice regarding PD in IS which is applicable to all situations [Puri et al., 2004].

Participation is often enhanced by the role of a mediator, or multiple layers of mediators. Different kinds of agencies may adopt varying strategies for mediation. In this case the NGO and the Community Health Workers were used as mediators. However, to be sustainable these mediators need to be part of civil society or governmental structures, so that when the NGO pulls out the IS doesn't collapse.

The role of a mediator in fostering participatory processes has received attention, to a limited extent, in contemporary IS literature. Puri shows [Puri, 2003] that the mediation role of the district administration was in acting like a bridge between scientific departments and the local Geographical Information Systems teams. The district administration also assisted in mediating between policy formulation of national government and its practical implementation at local level. The role of NGO's as a mediator is highlighted by Beck, Madon and Sahay in India, where the NGO assisted in the development of information strategies, such as audio forms of communication, to empower marginalised slum dwellers in Bangalore [Beck et al.,

forthcoming 2004]. In Mozambique the mediating role of the academia was to facilitate the linkage between health bureaucracy on one hand, and the communities and the local health workers on the other and was critical in creating the required environment for 'learning by doing' [Puri et al., 2004].

10.5 Going beyond formal communication

Communication involves more than the understanding of language used and includes the sharing of meanings. Within the literature on organisation as culture, there is the primary view that culture is shared meaning. Within an organisation this has led to studies interpreting, reading or deciphering patterns of symbolic discourse [Walsham, 1993]. Culture is an active living phenomenon. The enactment of meaning within an organisation is, at least partly, a collective activity which creates structures of shared meaning within an organisation. These structures, as illustrated through Giddens' Structuration Theory, change and are recreated over time through discursive and recursive action. Walsham notes, whilst addressing computer-based IS specifically, that IS plays a key role in the process of enactment and reality construction, yet the cultural metaphor in its symbolic form has received relatively little attention in the IS literature. One exception is the article by Feldman and March [Feldman and March, 1981] where information is viewed as embedded in social norms that make it highly symbolic. Other work is that of Lyytinen [Lyytinen, 1985] where IS are viewed as language-based systems and their use involves communicative acts which can be studied as a linguistic process. Few IS studies look at dialogue as an important part of the structuration process.

This case study found that one useful concept in exploring communication and shared meaning is that of Habermas' idealised public sphere [Habermas, 1989]. It is used to describe the attempts to create spaces where people can discuss their opinions and desires. The 'Ideal Speech Situation' is, as the name implies, ideal. Habermas does not claim that all communication boundaries can be surmounted in attaining this state. However, using the 'Ideal Speech Situation' as a strategy highlights the power relations in play in IS design.

In criticism of Habermas' account of the public sphere as one large forum where all participants are present, I argue that there is the need to view the public sphere as comprising smaller groups or 'sub-spheres' (similar to what Fraser [Fraser, 1993,

p. 123] calls 'subaltern counter publics'). In the 'Ideal Speech Situation' a consensus is not necessarily achieved, as it is the strength of the rational argument that ultimately decides on the agreed outcome of the discussion. Therefore if the approach of viewing the 'public sphere' as just one large group is taken, then the minority view will always be over-ruled. Using Structuration Theory to understand the systems and structures in such 'sub-spheres', and thereby, to what extent the conditions necessary for the attainment of the 'Ideal Speech Situation' (9.2) are met does, contrary to what Avgerou says, provide an adequate approach "for understanding the uneven processes of information systems innovation in the conditions of severe inequalities sedimented in the variety of institutions of the global context." [Avgerou, 2002, p. 11]

10.6 Scalability and sustainability

As argued by Braa, Monteiro and Sahay [Braa et al., 2004], two major challenges in the development of a successful HIS are the interrelated factors of sustainability and scalability.

10.6.1 Sustainability

Sustainability

...concerns the challenge to make an IS work, in practice, over time, in a local setting. This involves shaping and adapting the systems to a given context, cultivating local learning processes and institutionalizing routines of use that persist over time (also when researchers leave and external funding is over). [Braa et al., 2004, p. 4]

As Braa, Monteiro and Sahay posit, scalability requires local interventions to be part of, or connected to, broader networks for sustainability to occur [Braa et al., 2004, p. 4]. They argue that local action research interventions need to be conceptualised and approached as, but one element in a larger network of action in order to ensure sustainability. Sustainability cannot occur just through action at a local level, scaling needs to occur.

Often the problem with IS development projects, whether internally or externally funded, is the short term strategies adopted. There is a need for planning with

long term horizons that go beyond the duration of funding. Other factors which impact negatively on sustainability include: “The absence of the participation, capability and motivation of users and for institutional changes to be incrementally adapted” [Kimaro and Nhampossa, forthcoming, p. 4].

In this case study, TDCSP had strategies to achieve sustainability from the start of their involvement in the area (the initial HIS was developed as an intervention and became part of the District Department of Health within the first four years). This strategy was expressed through capacity development and building on existing structures through partnership development and participation, especially in terms of creating alignment of goals and visions at different levels in the health system. Nevertheless, there is still concern over sustainability given the changes within the Department of Health and the lack of clear direction for the Community Health Workers.

10.6.2 Scalability

Scalability “. . . concerns the problem of how to make one, working solution spread to other sites, and be successfully adapted there.” [Braa et al., 2004, p. 2]. However, this is not merely a technical problem, but encompasses a socio-technical network, comprising people, technology, processes and the institutional context [Sahay and Walsham, 2004]. Scaling relates to a process and this raises two interesting questions regarding this process: *what is being scaled?* and *how is it being scaled?* [Sahay and Walsham, 2004]

From this case study, the process of developing a CBIS needs to be scaled and not the product. Guidelines, based on two case studies have been written and are dealt with in more detail in the next chapter (Chapter 11, Section 11.2). The question, *how is it being scaled*, addresses many common concerns facing most development projects - doing the same type of work in less time, with fewer resources and covering a geographically larger area. Just as in the case of PD in IS there appears to be no single best practice for scaling which is applicable to all situations. The ‘cultivation’ approach, referred to above (Section 10.3.3) with respect to the debate over standardisation and localisation, is perhaps the most appropriate choice of approaches to scaling as well. In this case cultivation means a slow, incremental process of aligning actors, transforming social structure and information infrastructure to produce a negotiated outcome. The cultivation approach to information

infrastructure is also suggested by Sahay and Walsham [Sahay and Walsham, 2004] in their discussion on theoretical considerations on scaling of HIS. A flexible and adaptive process, which accommodates planned and unplanned events, or as Giddens would say, anticipated and unanticipated consequences [Giddens, 1984], needs to be adopted for scaling to occur successfully.

One important element of scalability, as Braa, Monteiro and Sahay emphasise [Braa et al., 2004], is the creation of multiple interconnecting networks. In recent years there has been an increasing debate on the role of marginalisation and globalisation. Globalisation has been accompanied by rising inequality [Madon and Sahay, 2002, p. 1]. Castells refers to the groups of people affected by this inequality as 'the Fourth World'. These people and regions in the world are excluded from the information and knowledge related flows associated with globalisation. For successful public debate and discussion to influence the dominant structures there is a need to connect with the broader networks in society. Castells [Castells, 2000a], along with other authors [Madon and Sahay, 2002, p. 5], would argue that a key factor in being included in the information society is the connection of individuals and society with networks of information. Castells [Castells, 2000a] explains how the structures in place in a global economy reinforce the exclusion of vulnerable people and how important it is to tackle this exclusion by ensuring that they are linked with the rest of the global network. Through access to broader networks of information, communities have the potential to make better arguments and to engage in the debates that affect them on an equal footing. ICT's can assist in this respect.

Equally important to connecting with global flows in the PHC sector, is the creation of networks within the National Health System. In this research connections were attempted with the higher level health systems by connecting community-based information with the health facility information; producing guidelines that could be used elsewhere for similar work, and presenting papers and the case study to different social development and academic forums. Even when adopting a localised action research approach connections with broader networks and generalisations from such work need to be made.

10.7 Conducting Action Research

This case study describes the methodological approach that can be taken using a participatory action research approach in IS design. The small incremental steps in an action research process have been outlined: developing a partnership; creating a vision; participatory diagnosing of the problem; action planning and implementation, and participatory evaluation. Each of these small incremental steps, take place in a flexible manner and are enacted as a team or partnership. It is essential to this to create networks at local levels, as well as more broadly. In this case study, the sharing of experiences occurred between all role players in the community, as well as sharing beyond the community, to enhance those broader networks. This necessity of building networks is not emphasised enough in action research. Network establishment or enhancement is especially important when considering sustainability and scalability of a project as discussed above (Section 10.6).

Participatory action research fits in with the Critical Social Theorist approach. Two important outcomes of the participatory action research process are addressing the problem and developing generalisations (practical and theoretical). A participatory action research approach supports the argument that theory and practice must be interconnected if the human condition is to improve. It is impossible to improve the human condition solely by critiquing ideology or theories. It necessitates becoming involved in real life situations (see Section 2.2.1).

10.8 Generalisation

¹ IS researchers have identified generalisations of results from interpretive case studies to be a significant challenge [Lee and Baskerville, 2003]; [Walsham, 1995]. The challenge of generalisations concerns how results from a particular case study, whether in terms of methodologies adopted or theoretical insights generated, can be abstracted, and applied to, other settings. Unlike positivist studies which rely on statistical generalisations [Baskerville, 1996], interpretive research poses different sets of challenges around generalisations, especially relating to what can be generalised, how and to what extent. This section of the chapter analyses what aspects

¹This section forms the basis of the following paper: E. Byrne and S. Sahay, *Generalisations from a qualitative South African information systems case study*, Proceedings of forthcoming IFIP9.4 2005 conference

of the research process and outputs can be generalised to the introduction of similar systems in other health districts of South Africa and to other IS related research settings.

One of the reasons as to why generalisations are not typically made from interpretive research is that generalisations are often narrowly, and arguably inappropriately, confined to a positivist view of research. Positivist studies generally adopt statistical-based approaches to develop mathematical relationships between independent and dependent variables, and extrapolate the results from the sample studied to the larger population within specified statistical confidence intervals [Baskerville, 1996, p.5]. Interpretive research has been criticised from this perspective for its results being “non-generalisable” to larger populations because its focus is “only” on a single case study or “only” one organisation [Baskerville, 1996, p.3]. Such an interpretation of generalisations is worth challenging from both a theoretical and empirical perspective. Empirical and theoretical generalisations from interpretive case studies are both necessary and possible, however, they require approaches different from those used in positivist studies.

Various debates exist over the question of the development of generalisations from interpretive research. These vary from “If there is a ‘true’ generalisation, it is that there can be no generalisation” [Lincoln and Guba, 1985, p.110], to Baskerville and Lees call for interpretive researchers to acknowledge the generalities of their work [Baskerville and Lee, 1999]. Much of this debate stems from the definition of generalisations used and varies with the epistemological approach of the researcher. Guba and Lincoln describe generalisations as “... assertions of enduring value that are context-free. Their value lies in their ability to modulate efforts at prediction and control.” [Lincoln and Guba, 1985, p.111] While not completely agreeing to the appropriateness of making generalisations from interpretive/qualitative case studies, they argue however about the need to develop “working hypothesis” which represent tentative assertions of the situation, which are uncovered and tentatively applicable to other situations. The transferability, however, depends on the similarities between the contexts referred to by Guba and Lincoln as ‘fittingness’. The concept of “working hypothesis” resonates with Geertz’s notion of “thick descriptions” of a particular phenomenon within a specific context [Geertz, 1973]. Another researcher who in reading the “thick description” can interpret similarities and differences between different contexts, and the level at which abstractions can be made

about applying generalised learning from one context to another.

Lee and Baskerville [Lee and Baskerville, 2003] provide a comprehensive review of generalisations in the IS field, and build upon the work of other IS researchers who advocate the need to develop generalisations from interpretive case studies [Walsham, 1995]. After exploring the philosophical foundations of different forms of generalisations, namely the positivist and interpretivist schools, Lee and Baskerville develop a framework of four different types of generalisations. They distinguish between the base from which the generalisation is being made, either empirical or theoretical, and the base to which the generalisation is being applied, again either empirical or theoretical. The four types of generalisations are thus empirical to empirical; empirical to theoretical; theoretical to empirical, and; theoretical to theoretical [Lee and Baskerville, 2003].

Drawing from Bhaskar's concept of generative mechanisms [Bhaskar, 1979], Walsham extends the notion of generalisations from interpretive case studies. Generalisations can best be viewed, according to Walsham, as 'tendencies' and are best "... seen as explanations of particular phenomena derived from empirical interpretive research in specific IS settings, which may be valuable in the future in other organisations and contexts." [Walsham, 1995, p.79]. Walsham outlines four types of generalisations from interpretive case studies: the development of concepts, the drawing of specific implications, the contribution of rich insight and the generation of theory. Integrating the idea of Lee and Baskerville [Lee and Baskerville, 2003] and Walsham [Walsham, 1995] helps to develop a framework around the 'categories' and 'types' of generalisations. This framework is presented in Table 10.2.

10.8.1 Empirical to empirical

Generalising from empirical to empirical statements involves the generalisability of data to a measurement, observation or other description within and beyond the domain from which the data were collected. These include:

- development of concepts: Walsham gives the example of 'informaté' from Zuboffs' work, which implies how through the use of computer-based IS certain processes or new activities can become visible, which in earlier paper-based systems were hidden.
- drawing specific implications in particular domains of action: An example given by Walsham of this type of generalisation is an in-depth case study

Types of generalisations	Category: Empirical to empirical	Category: Empirical to theoretical
Developing concepts	Developing single concepts or concepts as part of a broader network.	
Drawing specific implications	Drawing specific implications from particular case studies or research settings.	
Contributing rich insight	Insights that are neither concepts nor specific implications of theories.	
Generating theory		Communication framework using Critical Social Theory

Table 10.2: Category and types of generalisations

of IS development in a financial services company [Walsham, 1995, p.80]. In this study the relationship between the design and development process and business strategy is examined. An arbitrary methodological approach to computer-based IS development, with a clear business focus can result in rapid systems development, but can also lead to lack of integration and inflexibility. On the other hand if there is heavy reliance on formalised methods the IS development can be slow and time bound when the business vision and related IS strategy is unclear. The implication, in this study, is a good description of what Walsham terms a 'generative mechanism', which could be used in other organisations and contexts.

- developing 'rich insight': Giving the example of Suchmans' concepts of 'plans' and 'situated action', her various theories regarding human-machine interaction and specific implications, her contribution is described in this broader category of rich-insight [Walsham, 1995, p.80]. This type of generalisation is used to capture those contributions that cannot be easily described as concepts, theories or social implications.

In this case study the empirical to empirical generalisation relates to the manner in which participation was reconceptualised through this study and how this reconceptualisation has more general learnings to other settings. Participation was reconceptualised in at least four different ways:

- Involvement of the community is needed;
- Adopting a multi-level and multi-sectoral approach;
- Emphasising the political nature of the participatory process, and;
- Integrating participation with action research.

This is an example of the drawing of specific implications.

10.8.2 Empirical to theoretical

This category of generalisations includes the moving from the empirical base of a case study to a theoretical base by revising, editing, highlighting or generating theory.

- generating theory: This involves the generalisability of measurements, observations, or other descriptions to theory, and the generalisability of the resulting theory beyond the domain that the researcher observes. Walsham gives an example from Orlikowski and Robey's [Orlikowski and Robey, 1991] work in IS to construct a theoretical framework concerned with the organisational consequences of information technology. They suggested that this framework could be used in systems development and the organisational consequences of using IT.

An empirical to theoretical generalisation developed from this case study is the articulation of a theoretical framework for communication. The empirical work in the case study focussed significantly on the development of enabling conditions within which different relevant members could express their views and participate in the development of the community-based health IS. This process of creating these conditions corresponds to the theoretical notion of 'Ideal Speech Situation' articulated by Habermas. This is an example of the generation of theory.

Our empirical work provided insights to extend Habermas' ideas in two ways. One was the application of the criteria to a specific context in South Africa. Furthermore, the 'Ideal Speech Situation' is extended to specifically examine the "distortions" which occur in achieving the 'Ideal Speech Situation'. For example, our empirical work identified various distortions in terms of limitations faced when we had combined meetings with representatives of the community, project and district staff, on the determination of indicators. The people associated with the community were reluctant to offer suggestions on how the proposed data could be collected

and how best to define the indicators within this meeting. The combination of the different hierarchies in the group impeded full participation from all participants. Another potential distortion identified is the difficulty faced for many women to participate due to 'time-poverty' - that is, given the excessively long days that women work finding the time to participate in the forums established may not have been possible.

This notion of incorporating distortions within the 'Ideal Speech Situation' concept leads to a communication framework which can be usefully generalised in other settings. For example, in the Western world, distortions may arise from the time constraints members have to participate, while in other developing countries settings inadequate knowledge or poor infrastructure could potentially lead to distortions.

Table 10.3 summarises the particular generalisations from this case study.

Category of generalisation	Type of generalisation	Generalisation from case study
Empirical to empirical	Drawing of specific implications	Reconceptualisation of participation
Empirical to theoretical	Generation of theory	Communication framework

Table 10.3: Generalisations from the UThukela District case study

10.9 Conclusion

Table 10.4 summarises the main theoretical contributions made by this research. The main argument made here is for the adoption of contextual approaches to IS research. I propose the use of Structuration Theory, as an example of a conceptual process theory, that can be used effectively to understand the context of design. Structuration Theory also highlights the importance of communication, power and sanction in the creation and recreation of these structures. The interaction of human agencies through communication can be enhanced by striving for the 'Ideal Speech Situation' in small groups. Power can also be used by the marginalised in the attainment of their rights, if they participate in the design and develop their capacity. The support of a mediating agency can be of great value in enhancing this participation. IS design can be used effectively in human development as a powerful advocacy tool, if IS researchers adopt such a moral position. Lastly, for the IS to be sustainable it needs to be scalable. To attain this the system needs

to be embedded in broader systems and structures and empirical and theoretical generalisations need to be made from qualitative IS research.

Concept:	Theoretical contribution:
Giddens' Structuration Theory	Use in a South African context. Empirical basis of use in CBIS. Integration with Critical Social Theory.
Design of CBIS	CBIS not adequately addressed in IS design. Meaning of community. Integration of systems.
Participation in IS design	Extending debate to non-western contexts.
Communication	Going beyond formal communication.
Scalability and sustainability	Need for networking. Connecting with broader networks.
Action Research	Methodological approach elaborated.
Generalisation	Generalising from single case settings.

Table 10.4: Theoretical contributions of research

In terms of future work which can stem theoretically from this work there are three possible areas for development which I wish to explore:

- providing a stronger theoretical background to the use of participatory methodology in IS research and conducting more empirical work using this methodology [Korpela et al., 2004];
- exploring the debate on generalisations from interpretive research further, and;
- using the communication framework developed in this research in other empirical case studies.

Chapter 11

Practical contributions and conclusion

A number of lessons have been learnt from the process and output of the design and development of the child-health CBIS. In this chapter, I continue with the contributions of the research, but from a practical and empirical position, rather than from the theoretical stance of the previous chapter. This chapter, therefore, addresses the research question: **How can case experience from a localised setting be integrated into broader level structures to effect longer institutionalised change through practical generalisations?**

11.1 Introduction

The premise behind this research is that vulnerability of children can be tackled using two interconnected strategies. The first, is through the creation of awareness of the situation of children and the second, through mobilising the commitment and action of government and society to address this situation. The work in UThukela District aimed to design an IS for action that can be used for advocating and influencing decisions and policies for the rights of all children, especially the vulnerable. In the design and development of a CBIS for the care of vulnerable children, the necessity of a longitudinal, multi-sectoral and multi-levelled approach was acknowledged. This is not just in determining who should participate, how information should flow and in what format, or the development of an appropriate communication loop, but also, if restrictive structures are to be challenged, there is the necessity to link with broader networks.

The process of improving the health situation of children should begin with protecting their immediate environment - protecting their space at community level. In the long term, to have an impact on society, the structures that cause and generate the exclusion need to be redefined. To a certain extent, as I argue by advocating on behalf of children, this can be done by communicating with the government and other state structures. Ultimately, what needs to happen is for civil society to change, and for those very structures we are engaging with, to change, to form a society where children are valued and their rights are upheld and realised.

In UThukela District, as evidenced from the final evaluation of the project, there is an increased awareness in the community around the health and care of their children. The IS design process contributed to the generation of this awareness, but it also occurred through capacity development, which aimed at empowering communities to protect and care for their children. This effect is still localised and there is the need to go beyond that setting and impact on broader society. To learn from the experience in the localised setting, it is important to look at the possible differences and similarities of OKhahlamba Municipality with other settings. Of course, only those researchers who have knowledge of the setting in which they are going to apply some of the experiences outlined here, will be in a position to fully determine what those similarities and differences really are.

In line with the theoretical contributions of the previous chapter (Chapter 10),

I further examine the same categories in terms of the practical contributions which can be made from this research. I, thus, extend the discussion in the following areas where my research also contributed on a practical level:

- designing a CBIS using participatory action research;
- extending the debate on participation;
- going beyond formal communication, and;
- addressing scalability of CBIS.

11.2 Designing a CBIS using participatory action research

In an attempt to move beyond a localised setting and to impact processes and structures beyond UThukela District, I was commissioned to develop guidelines on monitoring and evaluating child-health for the National Department of Health. Part of this work included guidelines on how to develop a child-health monitoring and CBIS¹. The guidelines were based on the UThukela District experience and the experience in another province. As the research progressed, and during some retrospective analysis of that process with the research team and the national community child-health committee, a number of essential elements in the designing of a community monitoring and evaluation system emerged. These elements evolved and developed as progress was made and did not follow a rigid sequential order. Following the participatory action research framework a brief overview of the practical elements in such an incremental process is given here.

11.2.1 Client-system infrastructure

One of the first steps in the design of an IS is to obtain clarity over who needs to be involved in the process and to develop an understanding regarding respective roles and responsibilities. The identification of the key role players and potential partners could include:

- the calling of a meeting of interested parties from different sectors;

¹ *Guidelines on the design and implementation of a community-based child-health monitoring system* written by Elaine Byrne, on behalf of the National Department of Health and UNICEF, Pretoria, South Africa, 2004 (unpublished)

- identification of the key partners (duty bearers and role players);
- creation of forums or spaces where open discussion can take place;
- discussion of the resources available to the committee, and;
- the appointment of a focal person to coordinate regular meetings.

One strategy to get all role players together in the initial formation of the research, is the establishment of a multi-sectoral platform. It is important to link the activities in other sectors through this platform, to take into account available resources, local needs, capacities and to avoid duplication if such a platform or forum already exists. The people who should be represented in some capacity include (adapted from [McAllister and Vernooy, 1999, p. 9]):

- individuals and groups who can influence the outcome because of the power they hold, their ability to influence opinion, the useful knowledge or skills they possess (including leaders within the community, government officials, or other groups);
- individuals or groups who will be directly influenced by the outcome (including less powerful groups who may not be able to participate actively, but whose perspectives need to be considered, for example young children), and;
- individuals or groups who are willing or able to play a leadership role in social and environmental monitoring, problem solving and conflict management, for example the person who knows everybody at community level, an elderly or retired person.

It is also important that the forums for the meetings and discussions are carefully established so that open, free and fair discussions can take place.

11.2.2 Diagnosing

After the agreement on the roles and responsibilities of the various parties is reached, the research process needs to be planned. As the monitoring system is part of the planning process of the child-health intervention, a vision for any intervention needs to be determined before the issue of monitoring is tackled. It is important that all participants in the team have a clear understanding of what this vision means to them and have explored carefully the meanings other participants have of this vision. The vision needs to align with the various visions of the different levels and different sectors. If the visions of the various parties involved differ radically it is

not possible to generate a common group action theory and framework. “The use of participative design methods, in the absence of a shared vision for change, may not generate a consensus for action.” [Walsham, 2003, Table 9.3, p. 204]

It is important to remember that the purpose of developing a community-based child-health monitoring system is for the community to monitor themselves - it is not for the district or provincial officers to monitor their interventions at community level. In defining the objectives of, and the need for a CBIS, clarification needs to be reached on what the vision is, what needs to be monitored, why and for whom it is to be established. The use of participatory methods, such as mapping and gaps analysis, assist with the eliciting of different perspectives from different groups.

11.2.3 Action planning

Once there has been agreement on what the vision is, and who is to be involved, the required action needs to be planned. This can include the facilitation of community selection of possible measures or indicators to be included in the IS. This may need other interventions in terms of capacity development and the creation of an enabling environment for participation. This is discussed in more detail in Section 11.4.

Some assessment of the existing IS (formal and informal), including existing tools, methods and information flows would also need to take place. The aim here is to analyse both how information is accessed, shared and used, and the quality, source, availability and accessibility of that information regarding child 'well-being' and 'at-risk'. Participatory IS design should build on what people already know and do, using and developing people's current abilities and skills to monitor and evaluate their own progress, but also should take into account the systems, structures and institutions that already exist. The process of assessing the existing IS (formal and informal), including existing tools, methods and information flows includes an investigation of:

- What tools are used?
- Who are the main actors?
- Where does the data and information go and in what format?
- How was the system designed and why?

11.2.4 Action taking

After reviewing the existing IS, and the indicators selected have been refined, gaps in the existing system need to be identified. Once identified, a plan on how to address these gaps needs to be made. Attention needs to be given to the requirement for standardisation at the expense of losing some of the local particularity. Given the complexity of the health system, there is the need for one level of the system to be able to 'talk' to the other level. An important part of this communication channel is the standardisation of data elements, otherwise aggregating data would not be possible. However, there needs to be flexibility in terms of what people prioritise and the resulting data items to be collected in order to measure the progress towards the attainment of that priority.

Once agreement has been reached on the recommended changes to be made a plan needs to be made on how to implement the necessary changes. Usually there are existing structures which should be taken into account when considering change. This is where it is important to have the main duty bearers and rights holders involved in the process from the start as they will assist in guiding the process, as well as being able to assist with determining feasibility. Often changes need to be made in terms of the flow of existing information, rather than the introduction of more indicators. Simplification of existing IS is preferable to expansion. Once the framework has been developed a date needs to be fixed, and commitment from the key role players and duty bearers made, for the implementation of the changes. The appointment of an overall manager of the process allows for the monitoring of the implementation. After agreement is reached with the respective authorities the people involved in the process should be orientated on the changes.

11.2.5 Participatory evaluation and sharing of experiences

There is the need to conduct regular reviews and evaluations of the IS to see if it is meeting its objectives. Regular review meetings need to take place in the initial phases of implementation. The system needs to be continuously modified in the initial stages. A more thorough evaluation needs to take place approximately one year after the revised system has been implemented.

The review and evaluation of the revised system should be done in a participatory manner in order to get insight into what is actually happening and why, to get

greater ownership of the system, and to improve the chances of sustainability and use of the system. Capacity development would need to be considered in developing a team that would be able to carry out such a participatory evaluation.

Presentation and dissemination of the findings, for different levels and in different formats, is a critical aspect of the monitoring system that is commonly forgotten. Appropriate means of communication for the relevant users needs to be investigated. The purpose of this is to:

- ensure that time is taken to reflect on what has happened before engaging in new activities, or moving to new areas, and to ensure the system and experiences are embedded within the existing network;
- expand the network and share experiences so that others can learn from them;
- advocate for resources, or support, if needed, and;
- take appropriate action for the improvement of the health status of the children.

11.3 Extending the debate on participation

As was indicated in the case study described in this research using a human rights approach to IS design has a number of practical implications. A human rights approach makes mandatory the development of an IS that enables community voices to be heard in terms of their needs, interests, and expectations. In many ways this is similar to previous PD cases in IS research which questioned the issue of dominance, but this is usually from a workers perspective within an organisation. The fundamental difference between the perspective taken here and that of the traditional IS PD, is the normative stance taken on the fact that there is the obligation on the duty bearers to realise the community's right to participate and that this necessitates community involvement. This case study moved beyond the traditional parameters of PD - beyond the workplace where participation is viewed as a precondition for good design, to the community where we are legally and morally obliged to include the users of the health system.

Given the complexity of the health system, and the fact that communities are affected by factors and practices outside their control, a multi-levelled multi-sectoral approach to IS is required. Again I depart from conventional PD - moving beyond one organisation to a multi- levelled and multi-sectoral approach.

The design of IS is a social and political process. Participation of different community groups is required to address power imbalances. For this to happen, capacity to participate and an enabling environment, needs to be developed, as do the skills for using information for informed decisions. While access to information is a necessary pre-condition, on its own it is insufficient without the capacity to apply it in meaningful ways. This implies moving away from simple skills enhancement of workers which is often included in conventional PD approaches, to detailing the extent and type of participation, as well as including broader capacity development efforts to develop reflective-learning skills.

When adopting a Critical Social Theoretical perspective it is necessary to use a participatory approach to IS design. Participatory action research allows for both a theoretical and practical approach to address questions. The main departure points from conventional PD, as discussed in Chapter 8 and Chapter 10, are:

- the obligatory nature of community involvement;
- the need for a multi-level and multi-sectoral approach;
- the politics of participation and 'non-participation', and;
- the need to develop capacity for participation and for developing a climate for learning.

When using a participatory approach to systems design the researcher should clearly specify how the above issues were addressed

Participation is enhanced by creating appropriate channels of communication. Communication goes beyond the translation of concepts and meanings. Within the IS design process in this case study, the situation analysis and assessment enabled an understanding of how structures were shaped, as well as what structures exist and how they were formed. These existing structures were examined with the perspective of questioning and challenging some of them. Communication forms a very important mode for questioning and challenging these structures by allowing for the exploring, affirming or denying norms, debating policies and practices, and discussing old experiences and new ideas. Communication patterns reflect power relations within the community.

The communication patterns and traditional and cultural practices around communication are important in the designing of an IS that will be culturally acceptable and used. Building on and using traditional forms of communication can improve the chances of sustainability and designing an IS that is culturally and socially ac-

ceptable. Communication does not always work smoothly or in favour of children. Simply changing the information flow and improving participation are necessary for good communication, but are not sufficient. Communication loops need to be enacted between and within different levels. The necessary capacities to enable this to occur will also need to be developed. This would include the creation of an enabling environment for the various role players to meet. The principles for developing a public sphere and the criteria for the 'Ideal Speech Situation' have been discussed already in Chapter 9. These criteria can be used to monitor and evaluate the extent to which this environment enables free and fair participation and communication. To change any of the inhibiting structures of this enabling environment there is the need to go beyond the localised setting and to make connections with broader networks and systems.

Another key element in enabling participation is the development of the capacity to do so. One of the fundamental principles of TDCSP was the development of local capacities. In the final evaluation [TDCSP, 2004], this area of the projects work was praised for its intensity and breadth of scope. In the design and development of the CBIS, the main focus of the capacity development strategy was on:

- an understanding of IS and its use;
- training on data collection and analysis, particularly participatory techniques;
- training and discussion on child-health issues, and;
- dissemination and feedback techniques.

This focus on capacity development is in line with the human rights approach adopted. The identification of the duty bearers, within a human rights approach, is crucial, but the fulfilment of duties depends on capacity. Key to a human rights approach to development is capacity development. All people live in communities and development means development of people within those communities. However, these communities do not exist in isolation. They are linked through various and extensive networks with other communities and with other levels such as district, province and national. Capacity development must be for both the duty bearers and the rights holders at the different levels.

Capacity development goes beyond training and beyond the implicit assumptions of capacity building (where it is assumed that the community do not have any capacity at all to begin with and that the outsider is starting from scratch). As Suchman explains we need to move beyond the 'fallacy of the empty vessel':

... that is, the assumption by those who position themselves at the center of some form of knowledge production that there is no knowledge anywhere else, but only empty receptacles waiting to be filled. In other words, to put it bluntly, mistaking ones own ignorance of what exists elsewhere - knowledge, information systems, practices - for their absence. [Suchman, 2002, p. 4]

As Jonsson notes all capacity development should be empowering.

This requires that people, who are poor, i.e. lacking certain capabilities, should be recognized as key actors in their own development, rather than passive beneficiaries of transfers. As outsiders of a community we must respect the dignity of people, learn how to listen and perform a catalytic role in their own sustainable development. [Jonsson, 2000, p. 3]

How good empowerment is depends on who is empowered and what this power is used for. If those who gain exploit or dominate, whether as outsiders or as insiders, the poor and disadvantaged may be worse off. However

Empowerment, unless abused, serves equity and well-being. It is not a static condition. It is a process not a product; it is not something that is ever finished. ... Especially, it requires and implies changes in power relations and behaviour. [Chambers, 1999, p. 220]

Participation is thus fundamental, both in terms of understanding existing capacities, but also in developing new capacity. It is important to consider both the participation of community members in deciding and contributing to community actions, as well as the participation of the communities or their representatives in the broader social, political or economic developments affecting the community.

11.4 Going beyond formal communication

In the previous chapter (Section 10.5) the importance of understanding the language used between the people who will use the IS was emphasised. One concept explored to enable this understanding was the use of Habermas's notion of the 'Ideal Speech Situation'. Another is the development of the community's own indicators. In this case study, the process of developing community indicators occurred through

a number of steps: visioning; discovering and listening to various meanings of 'well-being' and 'at-risk'; exploring the circumstances for these conditions to exist, and; determining who can act to change the situation if they had the relevant information. An important aspect of communication was an understanding of the context in which the CBIS was to be developed and the exploration, through participatory techniques, of the meanings attached to issues concerning child health.

As discussed in Chapter 6 (Section 6.2.2), a careful balance must be reached between overemphasis on quantification and the needs of monitoring trends in the community. In this case study, community members felt that they were not looking for a value to be placed on childhood vulnerability or risk, but rather for the ability to track changes in this status and to know when action needed to be taken when a child was falling into risk or danger. It is possible, however, to generate an IS that does not include indicators as the following case example illustrates:

"A particularly innovative example has been developed by the Christian Commission for Development in Bangladesh (CCDB). Each credit group funded by the CCDB reports, on a monthly basis, the single most significant change that occurred amongst the group members related to: people's well-being, sustainability of people's institutions, people's participation, and one other open-ended change, if they wish. The report asks for the 'facts' (what, when, where, with whom) and an explanation of why that change is the most significant one of all the changes that have occurred. This last aspect ensures a process of reflection and learning by the group members, an aspect that is missing from most M & E (monitoring and evaluation) systems that seek numeric data without any interpretation of the numbers. So instead of pre-determined questions, CCDB's monitoring aims to find significant examples related to its long-term development objectives." [Guijt, 1998, p. 18]

11.5 Addressing scalability of CBIS

As described in the previous chapter (see Section 10.6.2), scalability "... concerns the problem of how to make one, working solution spread to other sites, and be successfully adapted there." [Braa et al., 2004, p. 2] One important concern in exploring these 'learning processes', or in developing generalisations, is the need to be

aware of the aspects of the context which are important in shaping the problem (infrastructure, available human, financial and time resources, language and culture). These aspects become points of reflection and analysis when one context is examined in relation to another. The complexity of the context requires an adaptable and flexible approach to the design and development of a CBIS. It is a time and resource consuming process. The availability of these resources, within the given context, affects the process, rate and order of progression.

Within South Africa, there are a number of broad similarities and differences between the OKhahlamba Municipality and other municipalities. The main difference between this municipality and others is the employment of Community Health Workers by the Department of Health. This cadre of workers, who used to be volunteers, or who worked with a local based NGO, have since 2002 been integrated into the workforce of the Provincial Department of Health. The Community Health Workers continue to be selected by the community in which they are to serve and the payment of the worker is by the Community Health Committee. The program is funded by the Department of Health. All Community Health Workers have received comprehensive training on health and community development topics. It is only in OKhahlamba Municipality that the Community Health Workers have been trained on data collection and data analysis techniques. Furthermore, not all municipalities have been as successful as UThukela District in the establishment of Community Health Committees and no other district has trained all the committees on child health. The Zulu traditions and cultures, as well as the language spoken, are similar within the rural areas of the entire province, but are very different to the urban areas and the other provinces. Combined with a very committed District Health Management Team, the long term presence of NGOs and support from local universities, a very strong, well-resourced district team exists.

There are, on the other hand, a number of similarities with other districts within South Africa. After 1994, the National Health Plan for South Africa and the Reconstruction and Development Programme outlined that a PHC approach is the underlying philosophy for the restructuring of the health system. As such there has been the movement from a traditionally vertical curative based health system to a newer client centred and preventive based health system. There has also been the movement towards the decentralisation of government, with the consequent formation of newly established structures, such as the Community Health Committees

and Forums. All districts within South Africa have adopted the strategy of IMCI. Community-based monitoring of child-health is an integral element of this strategy, as is the recognition of the importance of partnership development. Furthermore, all districts in South Africa, and most of sub-Saharan Africa, are facing the pandemic of HIV/AIDS, which has a significant impact at household level.

Given these similarities and differences, part of the process of scaling has been addressed within the district and beyond the district. These processes are briefly elaborated on below.

11.5.1 Expansion within the District

Within the UThukela District a meeting was held at the district office at the end of 2004 after the end-of-project evaluation had taken place. The purpose of the meeting was to coordinate community health data which is currently collected in the UThukela District. A review of the CBIS and their corresponding data collection tools, data flows and other artefacts, was conducted with the Community Health Facilitators and community programme managers from all the municipalities. After this review the participants agreed to adopt the IS that is implemented in the OKhahlamba Municipality and the observation forms and information flows would need to be adapted to fit in with the particularities of each of the other municipalities. Training on information collection and use for all the community programme managers and Community Health Facilitators would take place first. Once the community-based programme staff were clear on the CBIS, and how it could work, then it would be rolled out to the areas in which they are working

One reason why this meeting had not taken place earlier in the development of the CBIS was the absence of a District Information Officer for the duration of this research. This was a significant factor in the delay in the expansion of the CBIS to the rest of the district. The previous District Information Officer was promoted and a replacement was not found until September 2003. Another challenge faced, which arose in the meeting, was that the areas that the Community Health Workers are responsible for is not coterminous (having the same geographical boundaries) with the catchment areas of the health facilities. Therefore, matching community and facility data for the geographic areas below municipal level may be difficult. The potential of the child-health CBIS getting embedded into the UThukela DHIS is high, but the commitment of the District Health Management Team needs to

continue in order for this to happen.

As the CBIS relies heavily on a mediator between the community and the health authorities, there is the need to embed a culture of CBIS in the role of the community-based health workers. This could include cadres such as Community Health Workers and Home-Based Carers. Community Health Workers provided the essential link between the DHS and the community served by the health system. With the expansion of the tasks of these workers, less time is being left for data collection and analysis. The Department of Health needs to clarify its vision for community-based health workers. In the early drafts of the African National Congress's health plan community-based health workers were seen as an important part of the PHC service. They

... were seen as an important resource for PHC because of their potential to play a significant role in expanding and improving health services, provided they received effective support and ongoing training. They were viewed as catalysts for community development, who could mobilise people around issues such as the need for clean water, sanitation, waste disposal, safe playgrounds and parks. Further, they could empower people with health knowledge and encourage their participation in health issues such as nutrition, family planning and HIV/AIDS. It was envisaged that they would form an integral part of the decentralised health services, and be compensated, either by the Government, or the local community, according to their level of skills. This implied that they were to have career structures and pathways for promotion within the health system. [Friedman, 2002, p. 163]

However, in 1994, the official policy stated that the community-based health worker programmes would be encouraged, but that there would be no national programme. In 1995, a national task force, funded by the Health Systems Trust, produced a report *Assessing the Feasibility of Greater State Support to Community Based Health Programmes* which recommended that a phased model be considered for implementation by the national government. In 1996, the National Department of Health delegated the decision on the deployment of community-based health workers to provincial and district levels. Some provincial programmes are gradually developing, such as in KwaZulu-Natal, but even here the support has been patchy and inconsistent. Despite advocacy and some progress, uncertainty about precise

roles for community based health workers remains both at a national and provincial level. Clarity on the vision and the development of formal systems for the support of community-based health workers is needed if a CBIS is to be sustainable and scalable. The gains made in the development of the CBIS in UThukela District may be eroded if that clarity is not achieved soon.

11.5.2 Expansion beyond the UThukela District

Guidelines on developing a community-based child-health monitoring system have been written for the National Department of Health. These guidelines are only useful if they facilitate other districts and municipalities to commence with the development and design of their own systems. This is happening in one other province currently, the Limpopo Province, but needs to be more widespread if a national impact is to be made. Further assistance through mentoring, training, resources and skills may be needed - an assessment of the provincial capacity would need to take place with a commitment to act on the capacity gaps.

One area that still needs to be developed further and poses perhaps the greatest practical challenge is the integrating of the CBIS with the existing DHIS into a comprehensive DHIS. As mentioned, the incompatibility of the geographical boundaries of the Community Health Worker's area and that of the health facility means that the data from the CBIS cannot easily be integrated with the health facility data corresponding to the same households serviced. Currently, as there are no reporting or data requirements from the community to the district or province, this hasn't posed any problem. To go beyond one district would require a common vision from all the role players in each of the districts in the province and the endorsement of the province and other districts for the need for a CBIS. Possible tensions and problems may arise from trying to merge and bring together the biomedical, community and traditional views of information for child health at this stage. This may be attributed to the holistic view of health which the community have for child health and the biomedical, and hence narrower, view of health held by the health workers within the Department of Health. This has implications over the boundaries which will be set for the DHIS, as distinct to that which would be termed, or viewed, as an IS for social development.

11.6 Conclusion

The design and development of a child-health CBIS in UThukela District aimed to assist in the creation of awareness of the situation of children in the community through the data and information generated. This information could then be used as the basis for improving the situation of the children. The CBIS still faces a number of challenges in terms of access, autonomy, hierarchy, legal position and quality of participation (see Section 9.4). Even so, the work in UThukela District, though not replicable in its entirety, allows for generalisations to be made on two levels - theoretical and practical.

On a theoretical level the main contributions, as discussed in Chapter 10, are:

- extending the use of Structuration Theory, in conjunction with Habermas' Critical Social Theory, to the empirical context of South Africa;
- addressing the gap of CBIS in IS design;
- extending the debate on participation and communication in IS to 'developing' countries, and;
- developing generalisations from a qualitative case study.

There still needs to be more research in the area of CBIS and on developing generalisations. Using social theories, such as Structuration Theory and Critical Social Theory, in a participatory action research approach was found to be particularly appropriate in this area.

On a practical level the main contributions, as discussed in this Chapter, are:

- designing a CBIS using participatory action research;
- extending the debate on participation;
- going beyond formal communication, and;
- addressing scalability of CBIS.

In implementing these practical suggestions, commitment to the need for a CBIS is needed. Without this a CBIS will not succeed and will not be used to advocate for changes in the situation of children.

Lastly, I have been involved with the project for the last six years. In line with the interpretive approach adopted in this research, my interpretation of the data and texts is a reflection of my own embeddedness in the project. Other interpretations can also be developed from the account described in this thesis.

Part V

Bibliography

Bibliography

- J. Abbot and I. Guijt. Changing views on change: participatory approaches to monitoring the environment. *SARL Discussion Paper*, (2), July 1998. IIED, London.
- African National Congress (ANC). The Reconstruction and Development Programme. A policy framework, 1994.
- C. Avgerou. *Information Systems and Global Diversity*. Oxford University Press, Cambridge, 2002.
- D. E. Avison. The 'discipline' of information systems: Teaching, research and practice. In J. Mingers and F. Stowell, editors, *Information Systems: An Emerging Discipline?*, pages 113–136. Berkshire: McGraw-Hill, 1997.
- L. Bamford and M. Chopra. Developing a strategy for monitoring IMCI implementation in South Africa. Submitted to UNICEF, October 2001.
- R. Baskerville. Deferring Generalizability: Four Classes of Generalisation in Social Enquiry. *Scandinavian Journal of Information Systems*, 8(2):5–28, November 1996.
- R. Baskerville. Investigating Information Systems with Action Research. *Communications of the Association for Information Systems*, 2(19):1–31, October 1999.
- R. Baskerville and A. S. Lee. Distinctions among Different Types of Generalizing in Information Systems Research. In O. Ngwenyama, L. Introna, M. Myers, and J.I. DeGross, editors, *New Information Technologies in Organizational Processes: Field Studies and Theoretical Reflections on the Future of Work*, pages 49–65. Kluwer Academic Publishers, New York, 1999.

- R. Baskerville and A. T. Wood-Harper. Diversity in Action Research Methods. *European Journal of Information Systems*, 7:90–107, 1998.
- R. Bass. Habermas' Public Sphere. <http://www.georgetown.edu/faculty/bassr-/gaynor/publics.htm>, 2004. Accessed on July 23, 2004.
- E. Beck, S. Madon, and S. Sahay. On the margins of the 'information society': A comparative study of mediation. *Information Society*, forthcoming 2004.
- U. Beck. *What is Globalization?* Malden, MA:Polity Press, 2000.
- H. S. Becker. *Tricks of the Trade. How to think about your research while you're doing it.* The University of Chicago Press, Chicago and London, 1998.
- W. Beinart. Women in Rural Politics: Herschel District in the 1920s and 1930s. In B. Bozzoli, editor, *Class, Community and Conflict. South African Perspectives*, pages 324–358. Ravan Press Ltd, South Africa, 1987.
- M. Berg and E. Goorman. The Contextual Nature of Medical Information. *International Journal of Medical Informatics*, 56:51–60, 1999.
- Bergville District Child Survival Project. Detailed Implementation Plan. Bergville District, KwaZulu-Natal, South Africa, 1996a.
- Bergville District Child Survival Project. Knowledge Practice and Coverage survey. Bergville District, KwaZulu-Natal, South Africa,, 1996b.
- Bergville District Child Survival Project. Final evaluation report. Bergville District, KwaZulu-Natal, South Africa,, December 1999a.
- Bergville District Child Survival Project. Knowledge Practice and Coverage survey. Bergville District, KwaZulu-Natal, South Africa,, 1999b.
- R. Bhaskar. *The Possibility of Naturalism.* Brighton: Harvester, 1979.
- G. Bjerknæs and T. Bratteteig. User participation and democracy: a discussion of Scandinavian research in systems development. *Scandinavian Journal of Information Systems*, 7(1):73–98, 1995.
- G. Bjerknæs, P. Ehn, and M. Kyng, editors. *Computers and democracy.* Avebury, 1987.

- R. J. Boland. Phenomenology: A Preferred Approach to Research on Information Systems. In E. Mumford, R. Hirschheim, G. Fitzgerald, and T. Wood-Harper, editors, *Research Methods in Information Systems*, pages 193–201. Amsterdam:North-Holland,, 1985.
- R. J. Boland. Information system use as a hermeneutic process. In H. E. Nissen, H. K. Klein, and R. Hirschheim, editors, *Information Systems Research: Contemporary Approaches and Emergent Traditions*, pages 439–464. Elsevier Science Publishers B.V., North-Holland, 1991.
- P. Bourdieu. *Outline of a Theory of Practice*. Cambridge: Cambridge University Press, 1977.
- J. Braa. Community-based Participatory Design in the third world. In J. Blomberg, F. Kensing, and E.A. Dykstra-Erickson, editors, *Proceedings of the Participatory Design Conference*, pages 15–24. Cambridge, MA USA, 1996.
- J. Braa. Decentralisation, primary health care and information technology in developing countries: Case studies from Mongolia and South Africa. In *IFIP proceedings*, pages 130–142, 1999.
- J. Braa and C. Hedberg. The Struggle for District-Based Health Information Systems in South Africa. *The Information Society*, 18:113–127, 2002.
- J. Braa, E. Monteiro, and S. Sahay. Networks of actions: sustainable health information systems across developing countries. *MIS Quarterly*, 28(3), 2004.
- J. Braa and V. Shaw. Strategies to Prioritise the Fight against HIV/AIDS in National Routine Health Information Systems. In *Communication and Information Technology in the Global Fight against HIV/AIDS, Book of Abstracts*, page 18. HELINA Conference, South Africa, 2003.
- H. Bradford. 'We are now the men': Women's Beer Protests in the Natal Countryside, 1929. In B. Bozzoli, editor, *Class, Community and Conflict. South African Perspectives*, pages 292–323. Ravan Press Ltd, South Africa, 1987.
- E. Byrne. A human rights based approach to the development of a community information system for the care of orphans and vulnerable children in South Africa. In S. Krishna and S. Madon, editors, *Information & Communication*

- Technologies and Development: New Opportunities, Perspectives & Challenges*, pages 144–155. Proceedings of the seventh international working conference of IFIP (International Federation for Information Processing) 9.4, Bangalore, India, May 2002.
- E. Byrne. Addressing the Vulnerability of Children through Information Systems: A South African Case Study. In *Proceedings of SAICSIT (South African Institute of Computer Scientists and Information Technologists) conference*,, pages 33–43. Stellenbosch, South Africa, October 4-6 2004a.
- E. Byrne. Development through communicative action and information system design: a case study from South Africa. *South African Computer Journal (SACJ)*, 32:25–33, 2004b.
- E. Byrne. A participatory approach to the design of a community-based child health information system for the care of vulnerable children. <http://www.egov4dev.org/childhealthis.htm> & <http://www.e-devexchange.org/eGov/childhealthis.htm>, 2004c.
- E. Byrne and J. Gregory. Co-constructing local meanings for child health indicators in community-based information systems: the UThukela District Child Survival Project in KwaZulu-Natal. In *Proceedings of the ITHC 2004 conference: To Err is System, IT in Health Care: Socio-technical Approaches*,. Second International Conference, Portland, Oregon, USA, September 13-14 2004.
- E. Byrne and S. Sahay. Designing a community-based information system for the care of vulnerable children: generalisations from a South African case study. In *Communication and Information Technology in the Global Fight against HIV/AIDS, Abstract proceedings*, page 19. HELINA (Health Informatics Network for Africa), Johannesburg, South Africa, October 2003a.
- E. Byrne and S. Sahay. Health Information Systems for Primary Health Care: Thinking About Participation. In M. Korpela, R. Montealegre, and A. Poulymenakou, editors, *Proceedings of the IFIP TC8 & TC9/WG 8.2 & WG 9.4 Working Conference on Organizational Information Systems in the Context of Globalization, In-Progress Research Papers, Athens, Greece*, pages 237–249, 2003b.
- C. Calhoun, editor. *Habermas and the Public Sphere*. MIT Press, 1992.

- M. Castells. *The Information Age: Economy, Society and Culture: The Network Society*, volume 1. Blackwell Publishers, 2nd edition, 2000a.
- M. Castells. *The Information Age: Economy, Society and Culture Vol II: The Power of Identity*. Blackwell Publishers, 2nd edition, 2000b.
- R. Chambers. *Whose Reality Counts? Putting the first last*. Intermediate Technology Publications, 1999.
- P. Checkland. From Framework through Experience to Learning: the essential nature of Action Research. In H. E. Nissen, H. K. Klein, and R. Hirschheim, editors, *Information Systems Research: Contemporary Approaches and Emergent Traditions*, pages 397–403. Elsevier Science Publishers B.V., North-Holland, 1991.
- B. Chilundu and M. Aanestad. Negotiating multiple rationalities in the process of integrating the information systems of disease-specific health programmes. *Electronic Journal of Information Systems in Developing Countries (EJISDC)*, forthcoming.
- D. Cloete. From Warriors to Wage Slaves: The Fate of the Zulu People since 1879. *Reality*, 11(1), 1979.
- C. de Beer. *The South African Disease: Apartheid Health and Health Service*. Catholic Institute for International Relations, London, 2nd edition, 1986.
- Department of Health. White Paper for the Transformation of the Health System in South Africa. Republic of South Africa Government Gazette, 1997.
- Department of Health. National HIV and Syphilis antenatal sero-prevalence survey in South Africa 2002. Technical report, Directorate: Health Systems Research, Research Coordination and Epidemiology, 2002.
- P. Ehn. Scandinavian Design: On Participation and Skill. In Douglas Schuler and Namioka, editors, *Participatory Design: Principles and Practice*, chapter 4, pages 41–77. Laurence Erlbaum, 1993.
- M. Elden and M. Levin. Cogenerative learning - bringing participation into action research. In W. F. Whyte, editor, *Participatory Action Research*, chapter 9, pages 127–142. Sage Publication, 1991.

- M.S. Feldman and J.G. March. Information in organizations as signal and symbol. *Administrative Science Quarterly*, 26(2):171–186, 1981.
- B. Fitzgerald, N. L. Russo, and E. Stolterman. *Information Systems Development: Methods in Action*. McGraw-Hill, London, 2002.
- N. Fraser. Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy. In C. Calhoun, editor, *Habermas and the Public Sphere*, chapter 5, pages 109–142. MIT Press, 1993.
- I. Friedman. Community based health workers. In *South African Health Review*, chapter 9, pages 161–180. Health Systems Trust, 2002.
- C. Geertz. *The Interpretation of Cultures*. Basic Books, New York, 1973.
- C. Gibson, T. Kerry, and C. Kerry. Child Health Situational Analysis for oKhahlamba-eMtshezi. Written on behalf of the UThukela District Child Survival Project, November 1999.
- C. Gibson, T. Kerry, Z. Mchunu, Z. Khumalo, and C. Kerry. The household and community component of the Integrated Management of Childhood Illness (IMCI). Written on behalf of the UThukela District Child Survival Project. Phase II report - New research, November 2000.
- A. Giddens. *The Constitution of Society. Outline of the theory of structuration*. Cambridge:Polity, 1984.
- A. Giddens. A reply to my critics. In D. Held and J.B. Thompson, editors, *Social theory of modern societies: Anthony Giddens and his critics.*, pages 249–301. Cambridge Unniversity Press, 1989.
- A. Giddens. *The Consequences of Modernity*. Stanford, CA:Stanford University Press, 1991a.
- A. Giddens. *Modernity and Self-Identity: Self and Society in the Late Modern Age*. Cambridge: Polity Press, 1991b.
- S. Giese, H. Meintjes, R. Croke, and R. Chamberlain. *Health and Social Services to Address the Needs of Orphans and Other Vulnerable Children in the context of HIV/AIDS*. Children’s Institute of the University of Cape Town, January

2003. Research Report and Recommendations, Report submitted to the National HIV/AIDS Directorate, Department of Health.
- Government of South Africa Government Communications(GCIS). Poverty and Inequality in South Africa. Technical report, Report prepared for the Office of the Executive Deputy President and the Inter-Ministerial Committee for Poverty and Inequality, 1998.
- Government of South Africa. Constitution of the Republic of South Africa, 1996. Act 108 of 1996 as adopted on 8 May 1996 and amended on 11 October 1996 by the Constitutional Assembly.
- N. Gregson. On the (ir)relevance of structuration theory to empirical research. In D. Held and J.B. Thompson, editors, *Social theory of modern societies: Anthony Giddens and his critics.*, pages 235–248. Cambridge University Press, 1989.
- I. Guijt. Participatory monitoring and impact assessment of sustainable agriculture initiatives. *SARL Discussion Paper*, (1), 1998. IIED, London, UK.
- I. Guijt, M. Arevalo, and K. Saladores. Tracking change together. *PLA Notes*, 31 (1):28–36, February 1998.
- I. Guijt and A. Cornwall. Editorial: Critical reflections on the practice of PRA. *PLA Notes*, 24(1):2–7, October 1995.
- I. Guijt and M. K. Shah. Waking up to power, conflict and process. In I. Guijt and M. K. Shah, editors, *The Myth of Community. Gender issues in participatory development*, pages 1–23. ITDG Publishing, London, 2001.
- L. Gunner. Literary Afterword. In *Zulu Woman. The Life Story of Christina Sibiya by R. Reyher*, pages 199–210. The feminist press at the City University of New York, 1999.
- J. Habermas. *Theory and Practice*. Polity, Cambridge, 1973.
- J. Habermas. *The Theory of Communicative Action*. MIT Press, 1987.
- J. Habermas. *Structural Transformation of the Public Sphere*. Cambridge, Mass:MIT Press, 1989.

- R. Haynes and W. Hall. District Health Systems and Local Government Developments. In *South African Health Review*, chapter 5, pages 83–100. Health Systems Trust, 2002.
- Health Systems Trust and Department of Health. *District Health Information System Guidelines*, February 1998.
- R. Heeks. Information and Communication Technologies, Poverty and Development. *Development Informatics Working Paper Series*, (5), June 1999.
- R. Hirschheim and R. Boland. *Series Foreword*, pages xi–xii in *Interpreting Information Systems in Organisations* by G. Walsham. Chichester, John Wiley,, 1993.
- R. Hirschheim and H. Klein. Four paradigms of information systems development. *Communications of ACM*, 32:1199–1216, 1989.
- R. Hirschheim and H. Klein. Realizing Emancipatory Principles in Information Systems Development: The Case for ETHICS. *MIS Quarterly*, 18(1):83–109, March 1994.
- R. Hirschheim, H. K. Klein, and K. Lyytinen. Exploring the Intellectual Structures of Information Systems Development: A Social Action Theoretical Analysis. *Accounting, Management and Information Technology*, 6(1-2):1–63, 1996.
- HSRC. Nelson Mandela/HSRC Study of HIV/AIDS: South African National HIV Prevalence, Behavioural Risks and Mass Media. Human Sciences Research Council, 2002.
- P. Ijumba, A. Ntuli, and P. Barron, editors. *South African Health Review*. Health Systems Trust, 2002.
- K. Ivanov. Critical systems thinking and information technology - some summary reflections, doubts, and hopes through critical thinking critically considered, and through hypersystems. *Journal of Applied Systems Analysis*, 18:39–55, 1991.
- E. Jensen-Krige. *The Social System of the Zulus*. Shutter and Shooter, Pietermaritzburg, 1965. Third impression.

- M. Jones. Structuration and IS. In W. L. Currie and R. D. Galliers, editors, *Rethinking Management Information Systems*, chapter 5, pages 103–135. Oxford University Press, 1997.
- M. Jones. Information systems and the double mangle: steering a course between Scylla of embedded structure and the Charybdis of strong symmetry. In T. Levine, L. Levine, and J.L. DeGross, editors, *Information Systems: Current Issues and Future Challenges*, pages 287–302, 1998.
- U. Jonsson. Regional Director’s Presentation at the Second Regular Session of UNICEF’s Executive Board. UNICEF East and Southern African Office (ESARO), 18-20 September 2000.
- U. Jonsson. *Human Rights Approach to Development Programming*. UNICEF, Kenya, 2003.
- S. Kanungo. On the emancipatory role of rural information systems. *Information Technology and People*, 17(4):407–422, 2004.
- D. Kellner. Habermas, the Public Sphere, and Democracy: A Critical Intervention. <http://www.gseis.ucla.edu/faculty/kellner/kellner.html>, 2004. Accessed November, 2004.
- H. Kimaro and J. Nhampossa. The Challenges of Sustainability of Health Information Systems in Developing Countries: Comparative Case Studies of Mozambique and Tanzania. *Information Technology for Development (ITD)*, forthcoming.
- R. Kling. Computerization and Social Transformations. *Science Technology and Human Values*, 16(3):342–367, 1991.
- M. Korpela, A. Mursu, A. Soriyan, A. Eerola, H. Hakkinen, and M. Toivanen. Information systems research and development by activity analysis and development: Dead horse or the next wave? In B. Kaplan, DP III Truex, D. Wastell, AT Wood-Harper, and JI DeGross, editors, *Information Systems Research: Relevant Theory and Informed Practice*, pages 453–470. IFIP TC8/WG8.2 20th Year Retrospective, Manchester, UK, Boston, MA: Kluwer Academic, July 15-17 2004.

- M. Korpela, H.A. Soriyan, K.C. Olufokunbi, A.A. Onayade, A. Davies-Adetugbo, and D. Adesanmi. Community Participation in Health Informatics in Africa: An Experiment in Tripartite Partnership in Ile-Ife, Nigeria. *CSCW*, 7:339–358, 1998.
- A. S. Lee. A Scientific Methodology for MIS Case Studies. *MIS Quarterly*, 13(1): 33–52, 1989.
- A. S. Lee. Electronic Mail as a Medium for Rich Communication: An Empirical Investigation Using Hermeneutic Interpretation. *MIS Quarterly*, 18(2):143–157, June 1994.
- A. S. Lee and R. L. Baskerville. Generalizing Generalizability in Information Systems Research. *Information Systems Research*, 14(3):221–243, September 2003.
- U. Lehmann and D. Sanders. Human Resource Development. In *South African Health Review*, chapter 7, pages 119–133. Health Systems Trust, 2002.
- Y. S. Lincoln and E. G. Guba. *Naturalist Inquiry*. Sage Publication, 1985.
- K. Lyytinen. Information systems and critical theory. In M. Alvesson and H. Willmott, editors, *Critical Management Studies*, chapter 8, pages 159–180. Sage Publications, London, 1992.
- K. Lyytinen and H. K. Klein. The critical theory of Jurgen Habermas as a basis for theory of information systems. In E. Mumford, R. Hirschheim, G. Fitzgerald, and A. T. Wood-Harper, editors, *Research Methods in Information Systems*, pages 219–236. North Holland, Amsterdam, 1985.
- K. Lyytinen and O. Ngwenyama. What does computer support for cooperative work mean? A structurational analysis of computer supported cooperative work. *Accounting Management and Information Technology*, 2(1):19–37, 1992.
- K. J. Lyytinen. Implications of Theories of Language for Information Systems. *MIS Quarterly*, pages 61–74, March 1985.
- D. MacIssac. The Critical Theory of Jurgen Habermas. <http://physiced.buffalostate.edu/danowner/habcrittty.html>, Accessed November 2003, 1996.

- S. Madon. International NGOs: Networking, Information Flows and Learning. *Development Informatics Working Paper Series*, (8), March 2000.
- S. Madon and S. Sahay. An Information-Based Model of NGO Mediation for the Empowerment of Slum Dwellers in Bangalore. *The Information Society*, 18(1): 13–19, 2002.
- P. Magubane. *Vanishing Cultures of South Africa. Changing customs in a changing world*. Struik Publishers, South Africa, 1998.
- S. H. Mandil. The National Health Information System of South Africa (NHIS/SA): from conception to the start of implementation. Technical Report WHO/AOI/95.14, WHO, November 1995.
- S. Mathur, A. Malhotra, and M. Mehta. Adolescent girls' aspirations and reproductive health in Nepal. *Reproductive Health Matters*, 9:91–100, 2001.
- L. Mbigi. *Ubuntu. The African Dream in Management*. Knowledge Resources (Pty) Ltd., 1997.
- K. McAllister and R. Vernooy. *Action and reflection: A guide for monitoring and evaluating participatory research*. IDRC, Canada, September 1999.
- T. McCarty. *The Critical Theory of Jurgen Habermas*. The MIT Press, Cambridge, Mass., 1978.
- D. McCoy. Restructuring the Health Services of South Africa: The District Health System. In *South African Health Review*, chapter 7, pages 108–120. Health Systems Trust, 1999.
- R. McGee. Participation in Development. In U. Kothari and M. Minogue, editors, *Development Theory and Practice*, pages 92–116. Palgrave, Rochdale, 2002.
- E. Mosse and E. Byrne. Analysis of identity in HIS development: a case study from Mozambique. Working paper, 2004.
- E. Mumford. Participation - from Aristotle to today. In T. Bemelmans, editor, *Beyond Productivity: Information Systems Development for Organizational Effectiveness*, pages 95–104. Elsevier Science Publishers B.V., North-Holland Press, 1984.

- E. Mumford. The Participation of Users in System Design: An account of the Origin, Evolution and use of the ETHICS Method. In D. Schuler and A. Namioka, editors, *Participatory Design: Principles and Practice*, pages 257–270. Lawrence Erlbaum, NJ, 1993.
- M. D. Myers. A disaster for everyone to see: an interpretive analysis of a failed IS project. *Accounting, Management and Information Technologies*, 4(4):185–201, 1994.
- M. D. Myers. Qualitative Research in Information Systems. *MIS Quarterly* (21:2), MISQ Discovery, archival version, June 1997, <http://www.misq.org/misqd961/isworld/>. MISQ Discovery, updated version, February 13, 2003, <http://www.qual.auckland.ac.za>, June 1997. pp 241-252.
- O. K. Ngwenyama. The Critical Social Theory Approach to Information Systems: Problems and Challenges. In H-E. Nissen and R.A. Hirschheim H.K. Klein, editors, *Information Systems Research: Contemporary Approaches and Emergent Traditions*, pages 267–280. North Holland, Amsterdam, 1991.
- O. K. Ngwenyama and A. S. Lee. Communciation richness in electronic mail: Critical Social Theory and the contextuality of meaning. *MIS Quarterly*, 21(2):145–167, June 1997.
- K. Nygaard. The 'Iron and Metal project': The Trade Union Participation. In A. Sandberg, editor, *Computers Dividing Man and Work - Recent Scandinavian research on planning computers from a trade union perspective*, number 13, pages 94–107. Swedish Center for Working Life, Utbildningsproduktion, Malmo, Sweden, 1979. DEMOS project report.
- J. O'Brien. *Introduction to Information Systems. Essentials for the e-Business Enterprise*. McGraw-Hill/Irwin, 11th edition, 2003.
- W. Orlikowski and J. J. Baroudi. Studying Information Technology in Organisations: Research Approaches and Assumptions. *Information Systems Research*, 2: 1–28, March 1991.
- W. Orlikowski and D. Robey. IT and the Structuring of Organisations. *Information Systems Research*, 2(2):143–169, 1991.

- W. J. Orlikowski. The duality of technology: rethinking the concept of technology in organisations. *Organisation Science*, 3(3):398–427, August 1992.
- K. Pasteur. Tools for sustainable livelihoods: Livelihoods monitoring and evaluation. IDS, February 2001.
- A. E. Pettifor, H. S. Rees, A. Steffenson, L. Hlongwa-Madikizela, C. MacPhail, K. Vermaak, and I. Kleinschmidt. HIV and sexual behaviour among young South Africans: a national survey of 15-24 year olds. Technical report, Johannesburg:Reproductive Health Research Unit, University of Witwatersrand. Copyright Health Systems Trust, April 2004.
- Y. Pillay, D. McCoy, and B. Asia. The District Health System in South Africa: Progress made and the next steps. Report funded through USAID, July 2001.
- J. Pleck, F. Sonenstein, and L. Ku. Contraceptive attitudes and intention to use condoms in sexually experienced and inexperienced adolescent males. *Journal of Family Issues*, 11:294–312, 1990.
- S. Puri. *The Challenges of Participation and Knowledge in GIS Implementation for Land Management: Case Studies from India*. PhD thesis, Faculty of Mathematics and Natural Sciences, University of Oslo, 2003.
- S. Puri, E. Byrne, J.L. Nhampossa, and Z. Quraishi. Contextuality of participation in IS design - a developing country perspective. In *Proceedings of the PDC04, The Eighth Participatory Design Conference, Toronto, Canada, July 26-31 2004*.
- S. Robinson and M. Sadan. Where Poverty Hits Hardest. Children and the Budget in South Africa. Technical report, Idasa, 1999.
- J. Rose. Evaluating the Contribution of Structuration Theory to the IS discipline. In W.R.J. Beats, editor, *Proceedings of the 6th European Conference on Information Systems*, 1998.
- J. Rose. Towards a structural theory of IS, - theory development and case study illustrations. In J. Pries-Heje, C. Ciborra, K. Kautz, J. Valor, E. Christiaanse, D. Avison, and C. Heje, editors, *Proceedings of the 7th European Conference on Information Systems*, Copenhagen, 1999.

- Routine Health Information Network, editor. *The RHINO Workshop on Issues and Innovation in Routine Health Information in Developing Countries*, March 14-16 2001. The Bolger Center, Potomac, MD, USA.
- M. Ryan. Gender and Public Access: Women's Politics in Nineteenth-Century America. In C. Calhoun, editor, *Habermas and the Public Sphere*, chapter 5, pages 259-288. MIT Press, 1993.
- W. Z. Sadomba. Behind the iron curtains of care: Factors that affect Caregiver Compliance to Health Advice and Instructions in rural Zimbabwe. Commissioned by UNICEF, Harare, March 2001.
- S. Sahay and C. Avgerou. Introducing the Special Issue on Information and Communication Technologies in Developing Countries. *The Information Society*, 18: 73-76, 2002.
- S. Sahay and G. Walsham. Implementation of GIS in India: organisational issues and implications. *International Journal Geographical Information Systems*, 10 (4):385-404, 1996.
- S. Sahay and G. Walsham. Scaling of Health Information Systems in India: Challenges and Approaches. *Working paper*, 2004.
- A. Sen. *Development as Freedom*. Oxford University Press, 1999.
- R. Smart. Children living with HIV/AIDS in South Africa - a rapid appraisal. An Interim National HIV/AIDS Care and Support Task Team (NACTT) project report, 2000.
- L.A. Suchman. Practice-based Design of Information Systems: Notes from the hyper-developed world. *The Information Society*, 18(2):139-144, 2002.
- G. Susman and R. Evered. An Assessment of The Scientific Merits of Action Research. *Administrative Science Quarterly*, 23(4):582-603, 1978.
- TDCSP. Mid term evaluation report, UThukela District Child Survival Project. UThukela District, KwaZulu-Natal, South Africa,, December 2001.
- TDCSP. End project evaluation report, UThukela District Child Survival Project. UThukela District, KwaZulu-Natal, South Africa,, May 2004.

- M. Thompson. Cultivating meaning; interpretive fine-tuning of a South African health information system. Draft paper, 2003.
- A. Thornton. Does Internet Create Democracy? *Equid Novi: South African Journal for Journalism Research*, 22(2):126–147, 2001.
- UNICEF. *Children on the Front Line: The impact of apartheid, destabilization and warfare on children in southern and South Africa*. UNICEF, 3rd edition, 1989.
- UNICEF. Operationalization for ESAR of UNICEF global guidelines for human rights programming. draft 2, Regional Office (ESARO), Nairobi, 8 August 2000.
- UNICEF and NCRC. *Children and Women in South Africa: A Situation Analysis*. UNICEF, South Africa, June 1993.
- H. Verran. Re-Imagining Land Ownership in Australia. *Postcolonial Studies*, 1(2): 237–254, 1998.
- G. Walsham. *Interpreting Information Systems in Organisations*. Chichester, John Wiley, 1993.
- G. Walsham. The Emergence of Interpretivism in IS Research. *Information Systems Research*, 6(4):376–394, 1995.
- G. Walsham. IT and Changing Professional Identity: Micro-Studies and Macro-Theory. *Journal of the American Society for Information Science*, 49(12):1081–1089, 1998.
- G. Walsham. Development, global futures and IS research. In M. Korpela, R. Montealegre, and A. Poulymenakou, editors, *Proceedings of the IFIP TC8 & TC9/WG 8.2 & WG 9.4 Working Conference on Organizational Information Systems in the Context of Globalization, In-Progress Research Papers*,, pages 13–22. Athens, Greece, 2003.
- G. Walsham and C.-K. Han. Structuration Theory and Information Systems Research. *Journal of Applied Systems Analysis*, 17:77–85, 1991.
- G. Walsham and S. Sahay. GIS for District-Level Administration in India: Problems and Opportunities. *International Journal of Geographical Information Systems*, 10:385–404, 1996.

- L. Whittaker. *Information Systems Evaluation: a post-dualist interpretation*. PhD thesis, University of Pretoria, April 2001.
- L. Williamson and N. Stoops. Using Information for Health. In *South African Health Review*, chapter 6. Health Systems Trust, 2001.
- L. Williamson, N. Stoops, and J. Doherty. Using Routine Information to Evaluate the South African National PMTCT Pilot Programmes - Lessons and Challenges. In *Communication and Information Technology in the Global Fight against HIV/AIDS, Book of abstracts*, page 23. HELINA Conference, South Africa, 2003.
- T. Winograd and F. Flores. *Understanding Computers and Cognition, A New Foundation for Design*. Addison-Wesley Publishing Co. Inc., New York, 1987.
- M. Wittenberg. Decentralisation in South Africa. First draft. School of Economic and Business Sciences and ERSA, University of the Witwatersrand, Johannesburg, South Africa, May 2003.

Part VI
Appendices

Appendix A

Community health worker observation tool - Okhahlamba

