INTENTIONS, PILLARS AND PLAYERS

EDITED BY THERESA LORENZO

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FOREWORD BY UN SPECIAL RAPPORTEUR ON DISABILITY

The launching of the Disability Catalyst comes at a time when 24 countries in Africa have ratified the UN Convention on the Rights of People with Disabilities (CRPD). This increase in ratification makes the need for debate about the implementation challenges all the more critical.

A thorough understanding of the letter and spirit of the CRPD is needed by decision makers in all governments because it is states party to the CRPD who bear the responsibility for implementing the treaties they ratify.

A thorough understanding of the CRPD implies that inclusion of people with disabilities in development is understood by governments and civil society. It would also imply an environment of good governance that respects the participation of people with disabilities as equal citizens.

This makes the Disability Catalyst so important and timely because we need to add more voices to the discussion on disability in society and we need to raise awareness about disability and human rights and development.

We are all aware of the lack of inclusion of people with disabilities in the Millennium Development Goals (MDG) and that the global development community is moving towards a post-MDG discussion.

We must ensure that the exclusion of people with disabilities from such important global developments never occurs again.

This publication will assist the process of inclusion and will aid in the process of ensuring that Africans with disabilities have a stronger voice in the global discussions about their rights and development.

Shuaib Chalklen

UN Special Rapporteur on Disability

FOREWORD BY DEPUTY VICE-CHANCELLOR

The transformation of higher education institutions after 1994 has aimed to be more responsive – to contribute to the common good, and to instil a sense of citizenship and social responsibility in students. In so doing, attention has been paid to those social groups that have been marginalised and excluded. Disability constitutes one form of exclusion that is not always recognised as such because of a prevailing sense that it is an individual problem requiring medical and therapeutic care. The reality is that a large proportion of disabled youth are not in formal education and few are able to access higher education institutions (Department of Education, 2004; Cramm et. al. in progress).

However, rights-based approaches to disability place emphasis on inclusion, equality and socio-economic development. Disabled people should have access to education and lifelong learning, leading to fulfilment of potential, a sense of dignity and self-worth, and effective participation in society (WHO, 2010). The UN Convention on the Rights of Persons with Disabilities (UN, 2006) is the first legally binding instrument to state specifically the right to inclusive education. Article 24, on education, indicates that state parties shall ensure an inclusive education system at all levels so that support is provided in environments that maximise academic and social development (UN, 2006). In addition, none of the Millennium Development Goals will be achieved without the inclusion of disabled people.

The initiation of Disability Catalyst Africa provides a vehicle for scholars across the continent to engage in collaborative research and teaching that will produce graduates who are able to contribute to disability-inclusive development. To make a difference in the lives of disabled people and their families such inclusion needs to happen at all levels of government as well as communities. Academics and students are in a good position to contribute to research that will monitor social change through effective collaboration with local government and civil society organisations.

The leadership of the university supports this endeavour wholeheartedly

in the belief that justice for disabled people is a necessary element for socially engaged scholarship.

Professor Thandobantu Nhlapo

Deputy Vice-Chancellor

References

Cramm, J., Nieboer, I., Anna, P. Finkenflügel, H. & Lorenzo, T. (in progress). "Disabled youth in South Africa: Barriers to education" in *International Journal on Disability and Human Development*, accepted for publication in January 2013.

Department of Education (2004) *Education White Paper 6: Building an inclusive education and training system*, South Africa: Government Press.

UN (2006) *Convention on the Rights of Persons with Disabilities* www.un.org/esa/socdev/enable/rights/convtexte.htm

WHO (2010) *Community Based Rehabilitation Guidelines*, WHO: Geneva

FOREWORD BY DEPUTY DEAN

Two years ago I had an accident, broke my leg and was forced to be in a wheelchair or hobble on crutches for more than six weeks. For the first time I was confronted with the reality of being a disabled person. My life seemed to change completely. It would seem the moment I was in the wheelchair – I lost the ability to speak, hear or sometimes see. People suddenly addressed the person pushing me in the wheelchair rather than me. The person at the check-in desk at the airport asked the person behind me for my ticket and passport and where I was going. Spoke loudly as if I were deaf.

One day, while shopping, my 12-year-old niece was pushing me and she was the one asked questions that should have been addressed to me. The ultimate insult came from a cashier – when my friend handed her my credit card and she processed the payment she asked "Can she sign?"

This is the humiliation that disabled people face on a daily basis. We need to challenge and change current societal responses to disability. It is in this context that Disability Catalyst Africa (DCA) assumes enormous importance as a mechanism to challenge civil society and government with respect to its response to disability.

This publication arises from a project on Disability Inclusion in Research (funded from the University of Cape Town Vice Chancellor's Strategic Goals Fund), to engage staff and students at higher education institutions with disabled people's organisations. Its purpose is to create awareness about disability and inclusive development, foster critical debate to produce new knowledge and facilitate self representation of people with disabilities in academic and public forums.

It is often said that one should measure the extent to which a country values respect for human rights by the way in which the most vulnerable sections of its population are treated. Unfortunately, in this respect, South Africa comes up short. Despite a very progressive constitution, the most vulnerable people in our country – children, the aged and the disabled – are often the most badly treated. This publication seeks to highlight the ways in which we succeed and fail in our duties as a country with respect

to disability and to bring to our attention ways in which we can improve our performance.

DCA provides a platform for Higher Education Institutions (HEIs) to give effect to the slogan of Disabled People South Africa (DPSA), "nothing about us without us", and work with disabled people's organisations to ensure that the mandate of HEIs to teach, research and respond to societal needs with respect to disability are met. Disability needs to be part of curricula, not just in the Faculties of Health Sciences, but equally in every faculty in all the HEIs.

The authors of this initiative are to be congratulated. The first issue has a variety of articles that point to the direction the publication seeks to go in providing a space for critical dialogue and the development of theories that reflect African realities. The challenge for us all is to see that the dialogues, debates and suggestions for policy changes do not remain in the realm of academia but become part of society and implemented to ensure equity, justice and dignity for all.

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CONTRIBUTORS

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Theresa Lorenzo, Associate Professor in the University of Cape Town's Disability Studies and Occupational Therapy department, gained experience in community-based disability and development programmes in the rural communities of Limpopo and Mpumalanga. She joined UCT's occupational therapy department in 1996 and has worked with the SACLA Health Project in building students' capacity to work with civil society organisations in addressing the needs of disabled people and their families. She initiated the Disability Studies Postgraduate Programme at UCT in 2003 to bridge the gap between activism and scholarship.

Judith Mckenzie

From 1998 to 2008 Judith Mckenzie taught at Rhodes University and the University of Fort Hare in inclusive education. In 2009 she was awarded

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Sarah Rule is the director of a non-governmental organisation, CREATE, in KwaZulu-Natal, where she collaborates with the Office of the Premier on advocacy for disability rights and is involved in several disability and rehabilitation training and research projects. She is also an honorary senior lecturer at the School of Health and Rehabilitation Sciences at the University of Cape Town.

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Ruth Watson is a retired occupational therapist and academic. Her research, writing and teaching of graduate students focuses on occupation-based practice through different forms of service delivery to disabled people. This is motivated by a concern for the impact that chronic and structural poverty have on human endeavours.

Chapter 1

THERESA LORENZO

INTRODUCTION

Disabled people are recognised as a vulnerable group in the United Nations' (UN) international conventions as well as the Constitutions and Bills of Rights of South Africa and some other African countries. Two aspects that need to be addressed are the rate and progress of policy implementation as well as the inclusion of disability issues at all levels of government and civil society. The paradigm shifts that have taken root have resulted in disability being viewed not only as a medical issue, but also as a social construct determined by cultural influences and belief systems. These shifts impact on service delivery and access to resources that would facilitate the participation of disabled children, youth, adults and elderly in activities and events in their communities. As such, disability needs to be seen in the context of general inequities in health, education, social development, employment and human settlements to name some of the critical areas concerned with the needs of vulnerable and marginalised groups. The power relationships between people with disabilities and non-disabled activists, academics, researchers and practitioners in the health, education and social development sectors and business sector remain contested.

KEY PURPOSE

A catalyst is a trigger or spark that prompts change. It can be seen as a means, method, mechanism, channel or vehicle for shifting the status quo in prevailing ways of thinking and acting. Disability Catalyst Africa (DCA) has two key purposes. The first is to provide the leadership of higher education institutions, civil society organisations (CSOs) and government, especially at local government level, with a conceptual and practical tool that they can use to support the advancement of disability inclusion in all activities, services, information and documentation of their institutions. Combining advocacy and capacity-building of relevant stakeholders, DCA will foster disability-inclusive teaching, research and social responsiveness. The second purpose is to create interactive spaces and processes for debate among key stakeholders through which economic, social and political resources within and across different sectors may be mobilised. These processes would contribute to furthering disability rights not just in response to other gauges or as an add-on to other monitoring instruments, but also as spaces to consider the complexities of change and sharing of power. By providing an opportunity to take a critical standpoint, DCA will disseminate essential information on disability debates relevant to Africa to a wider academic and public audience. Presented in a practical, useful and systematic format, the information will offer a framework for thinking and suggestions for collective action and evidence-based advocacy.

INTENTIONS

DCA intends to create reciprocal capacity building of different stakeholders to engage in disability matters with confidence in three ways:

Generate awareness of disability in development

Greater clarity about the concept of and need for disability equity has arisen following the ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD) (2006) by many African governments since 2008. New ways of thinking about disability have opened up opportunities to shift spaces and reorient the planning of environments in ways that will build a culture of support, raise awareness to overcome stigma, change belief and value systems, and generate organisational commitment to disability-inclusive policies and practices. In this way, the debate on disability will be elevated to the next level by engaging key people on issues of policy and programme implementation.

Foster critical debate to produce new knowledge

The voices of disabled people will be strengthened by bringing together role players beyond the leadership of the disability rights movement to debate policy issues. The construction of contextually appropriate frameworks and approaches to disability in Africa is envisioned. Learning from other places and contexts will develop capacity for disability inclusion across a diverse social and institutional landscape. The potential of theory building to effect social change will be encouraged by including "grey" research from non-governmental organisations (NGOs) and undergraduate projects.

Facilitate self-representation in academic and public forums

Giving voice to experiences of social inclusion, exclusion and oppression by disabled people, including children and/or their parents, is a priority. Different disability actors and organisations need to make the relevance of disability more visible to different stakeholders so as to broaden the debate outside of the disability movement. Bridging the silos that exist within the disability movement and related services will promote the inclusion of marginalised voices on disability issues. Debates will examine assumptions that underlie policy and practice thereby highlighting the

polarisation of issues, such as language of 'us and them' and 'impairment categories' rather than 'equal opportunities'. Reciprocal capacity building to address disability matters will occur as disabled people's organisations engage with academics, students, service providers and policy makers in debates to enhance each other's capabilities.

These intentions give voice to the principles and values encapsulated in the three pillars that will guide the production of each issue of DCA.

THREE PILLARS OF DCA

There exists a core of disability issues which should be negotiated to include thorny and silenced perspectives so that the complexity of disability discourse is expanded and the resilience of disabled people and their family members is foregrounded. DCA will attempt to illustrate the complexity of context and appraise the current state of affairs, and will highlight contradictions in policy and controversies in rights-based approaches. By exploring power relations in who defines disability, it will engage discourse about disability as well as pose questions that organisations need to ask themselves and each other if the vision of greater participation and opportunities for disabled people is to be realised. To achieve its purpose and intentions, the design and structure of DCA will take the disability debate beyond the confines of academia to embrace CSOs and local government structures through three mutually constituted pillars: affirmations, advocacy and accountability.

Affirmations

DCA intends changing ways of thinking about disability through shifting mindsets about disability. The chapters in each issue will highlight successes by individuals and collectives that are making transitions to social inclusion of disabled people. Contributors will report on examples where shifts and changes at individual, family, community and society level have occurred, or challenge instances where this transition is not happening.

The process will involve roundtable discussions with academics, postgraduate students, service providers, disabled people's organisations and government representatives.

Advocacy

Advocacy is a critical part of citizenship as it gives marginalised people

a voice, yet disability is a space that activists with other agendas do not necessarily consider. Equality is an aspiration. If the aspirations of equal citizenship for disabled people are to be realised, issues of power that exclude disabled people from participation, even within the disability movement, need to be unmasked. Disabled people need to claim citizenship for themselves. Each person is responsible and contributes towards building togetherness. The cornerstones of society are dignity, respect, compassion, caring and justice (Teffo, in Makgoba, 1999). DCA will seek to bring understanding to the complexities of difference and ability. There is a need to explore answers to questions such as What is holding back change? and What would make change possible?

Accountability

The Universal Declaration of Human Rights and the CRPD provide a framework to appraise society's actions related to creating disability-inclusive environments. Accountability needs to be reciprocal and respectful among stakeholders. Disabled people are seen as a disadvantaged social group in relation to the design and distribution of resources and programmes, compared to more advantaged groups. As a mechanism to guide research and monitor service delivery, DCA will promote accountability of government in policy-focused strategies that address the needs of disabled people. This section will inform changes in the degree of marginalisation and achievement of equality of disabled people in an African context. Correlations exist between disability and race, age, education, income, ethnicity, living arrangements and gender. Yet data is seldom disaggregated for disability as it is for gender, race and religion. Even within the disabled population, there is a hierarchy of need. The production of DCA offers higher education institutions a mechanism for engaging with CSOs and local government for mutual accountability regarding disability inclusion.

Each contribution aims to pose questions related to the three pillars, which are critical for the social inclusion of people with disabilities, particularly those whose impairments are largely hidden, such as intellectual and psychosocial. The vulnerability of disabled people, especially those with psychosocial or intellectual impairments, who experience more exclusion due to the invisibility of their impairments, can be addressed in four ways:

- Societal attitudes: personal contact shifts attitudes more than just knowledge. Therefore create opportunities for interaction.
- Reduce vulnerability by addressing the nature of the need for protection by sharing knowledge, skills and contacts.
- Substitute decision-makers need to see themselves as equal partners.

• Create opportunities for self-advocacy through local solidarity and dissemination of success stories and positive role models so as to influence policy and budgets at national level.

LOCATING THE INAUGURAL ISSUE

This issue of DCA presents the vision and formats of future issues.

The contributions in this issue synthesise relevant information and illustrate how we hope to disseminate it in an accessible manner to people who make decisions, plans and programmes. Sarah Rule accounts for the contributions that three main stakeholders could make to disability transitions, namely higher education institutions, CSOs and local government. Currently much information is not analysed and cannot demonstrate effective action that is already being taken. Information needs to be collected routinely to provide data and statistics on the violation or fulfilment of disabled people's rights. Judith Mckenzie explores the role of parents' organisations in relation to the social movements advocating for disability transformation. Mzolisi ka Toni and Harsha Kathard give a succinct account of the changes achieved by the disability movement in Africa, as well as current challenges. Madeleine Duncan, Kate Sherry and Ruth Watson explore the realities and assumptions about disability in rural and urban contexts. Lana van Niekerk gives a taste of the potential contribution of DCA in providing an overview of the challenges in employment equity for disabled people.

To influence change in social inclusion, the current situation needs to be appraised so as to identify gaps and monitor change over time. What needs to be debated is the nature of the measurements used, which is influenced by the different understandings of disability. Marguerite Schneider and Judith van der Veen provide two perspectives on processes of monitoring and measurement. In thinking about the information that is collected through government and CSOs, and how this information is used, questions that may be considered include: Can everything that is important be measured? Is everything that is measured important? What indicators will guide policy implementation to address non-delivery issues that are structural concerns to disabled people?

CONCLUSION

The production of DCA creates a space to translate the voices and experiences of disabled people, who are often invisible and marginalised, into conceptual tools and instruments that can be used to monitor the accessibility of activities, services, information and documents so as to facilitate participation of disabled people.

By providing a space for critical dialogue, contributors to each issue will interrogate the relevance of existing theory and the way knowledge about disability is constructed for an African context. The intention is not merely to simplify to make accessible; it will also present the complexities of the subject matter.

By putting research findings on a multitude of social issues in the public domain, different role players and stakeholders will be able to monitor progress in implementing disability-inclusive policies and programmes. These processes will produce evidence-based advocacy that affirms individual and collective successes so as to engender and mobilise disability-inclusive activism. The outcome will generate agents of change who are able to craft supportive regulatory frameworks to help monitor service provision and hold one another accountable.

It is anticipated that by translating a diversity of voices and experiences into conceptual tools through interdisciplinary research, new disability theory will be generated that can build common understanding on disability to achieve social justice for marginalised groups.

We hope this ignites your creativity and your ability to imagine new possibilities for all.

REFERENCE

Teffo, L.J. (1999) "Moral renewal and African experience(s)" in M.W. Makgoba (ed.)
    African Renaissance: The new struggle, Sandton: Mafube / Cape Town: Tafelberg.

Chapter 2

SARAH RULE

DISABILITY INCLUSION: A POSSIBLE MISSION?

With South Africa's ratification of the United Nations' (UN) Convention on the Rights of Persons with Disabilities (CRPD), the country is required to report to the Committee on the Rights of Persons with Disabilities every four years. Linked to this process is the possibility that civil society produces a shadow or parallel report which provides a commentary on the government's report. Capacity of civil society organisations (CSOs) needs to be developed to enable them to provide these alternative reports. Higher education institutions (HEIs) are positioned to play a major role in building this capacity for change through equipping staff and students with knowledge, skills and attitudes that foster disability mainstreaming in policy processes and research activities as well as professional practice. The role of government is to develop legal policy frameworks that formalise relationships; it is responsible for developing systems and services that affect us directly. Civil society develops social networks and relationships that affect our daily lives. Both government and civil society need to enable disabled people's active participation so that there is a sense of authentic belonging as citizens.

CAPACITATING HIGHER EDUCATION INSTITUTIONS

HEIs in Africa are at the forefront of research and the training of professionals to serve society. As such they are in a powerful position to influence opinion and contribute to the development of a critical discourse around implementation of Africa's progressive policies. These institutions are well positioned to make significant contributions to the debates on disability and social justice if they create spaces and environments that engender participation and stimulate thinking and action around disability issues. Key debates in the disability sector should inform research undertaken at HEIs. DCA aims to give pointers for further research by academics and students that could contribute to knowledge generation about policy implementation gaps and structural concerns about service delivery that foster disability access. The feasibility of disability as a disaggregate in data analysis, as is race and gender, should be explored by all researchers if research is to be relevant to the population.

Dealing with disability in its entirety and the various implications for different academic disciplines remains virgin territory. There is a need to stimulate different faculties within HEIs to engage with the complexities of disability issues in teaching and research if we hope to create graduates who are conscious of the rights of all citizens. The need for spaces where

academics and researchers engage with the disability movement through forums, roundtable discussions, debates and seminar series will make the mission of disability-inclusive development possible.

Lastly, DCA offers a mechanism for self-accountability of an HEI as it examines its progress towards inclusion of disability as an issue of diversity and transformation, as well as equity for disabled staff and students in all its structures and functions (Watermeyer et.al., 2006). HEIs have an imperative to engage in socially responsive teaching and research to generate evidence-based advocacy and research with CSOs and local governments.

ENGAGING BROADER CSOS AND ALLIANCES

CSOs, including disabled people's organisations, non-governmental organisations (NGOs), community-based organisations, faith-based organisations and others play an important role in the disability and development landscape in Africa (Watermeyer et.al., 2006). Some CSOs play a watchdog function, keeping an eye on government's policy making and implementation. Linked to this, they may be involved in advocacy, research and/or information dissemination. Some NGOs in Africa play a direct role in service provision, particularly in areas where government services are lacking.

The work of CSOs in creating an inclusive society needs to be made more visible, valued and appreciated. Showcasing changes in the situation of disabled people at various levels may provide evidence for the advocacy work of CSOs. The discussion of issues of equity and mainstreaming disability concerns may also prove to be useful as a tool for social mobilisation. It is hoped that the exploration of disability issues from multiple points of view will stimulate research, especially on issues related to the inclusion of disability in social and economic development and the fight for social justice for all.

Over the years, a number of CSOs have highlighted government's inadequate implementation of policies and legislation that promote inclusion of disabled people, without necessarily having more than anecdotal evidence to back up their claims (Umgungundlovu Disability Forum, 2010). The development of indicators has been fraught with difficulties. Collaboration offers opportunities to develop knowledge and technical skills to monitor change in policy implementation by government, as well as the

ability of CSOs to monitor their own activities and processes and report to donors who demand evidence of change.

AN ACCOUNTABLE, LOCAL GOVERNMENT

Local government is the site of most service delivery in African countries. Its responsibility is to implement policies and legislation which may have been determined at provincial or national level. Many local authorities may not have baseline data on the inclusion of disabled people in their area. HEIs have a potential role to assist with setting up systems for gathering information to monitor the implementation of policies and legislation with regards to disability access. Ongoing monitoring will create a barrier-free environment and equal access to services, activities, information and resources. The chapters in each issue of DCA aim to guide the gathering of such information which can form the basis of implementation plans related to the integrated development plans of each local authority. Promoting inclusion of disability issues in the integrated development plans of municipalities in local districts with illustrations of how it has been done in various contexts will hopefully improve service delivery and implementation of policies and legislation for inclusive development.
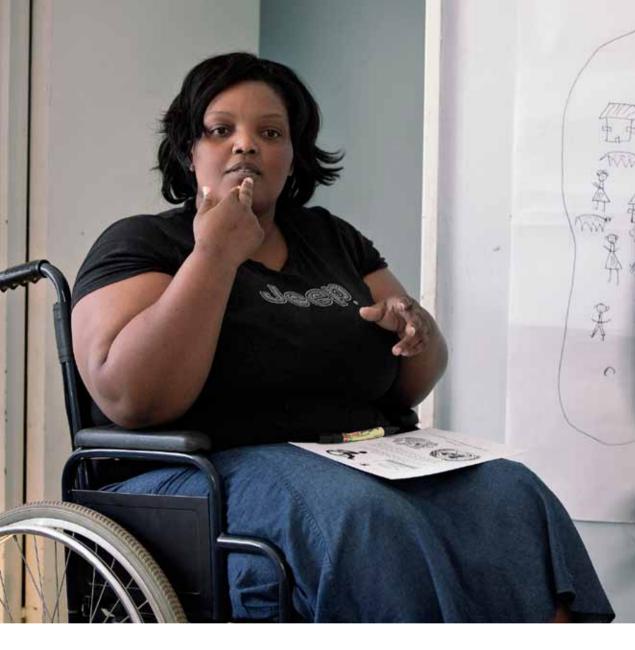
There is a need to foster mutual accountability through monitoring the implementation of policies and legislation. Where disability focal persons are employed in governance structures at different levels or in different institutions, these people often have little support or few tools at their disposal that they can use to support their positions and raise awareness among and across different sectors. DCA can be used extensively as a tool by each disability focal person in local government. Over time, the synthesis of information may facilitate comparisons across municipalities and districts which, in turn, may assist provincial governments in assessing the performance of the district municipalities in their jurisdiction. This action will inform decision making, particularly with regard to services and information that affect disabled people.

REFERENCES

Howell, C. (2006) "Disabled students and higher education in South Africa" in B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider & M. Preistley (eds), *Disability and Social Change: A South African agenda*, Cape Town: HSRC Press.

Masakhwe, P., Dube, A.K. & Mwangi, J. (2008) "DPOs' role in policy development and implementation of CBR" in S. Hartley & J. Okune, *CBR: Inclusive policy development and implementation*, University of East Anglia: Norwich.

Umgungundlovu Disability Forum (2010) "Shadow report to the Committee on the Rights of Persons with Disabilities" (unpublished report).

Watermeyer, B., Swartz, L., Lorenzo, T., Schneider, M. & Preistley, M. (eds) (2006) *Disability and Social Change: A South African agenda*, Cape Town: HSRC Press, 2006.

Chapter 3

JUDITH MCKENZIE

DISABILITY ACTIVISM AND PARTICIPATION

Within a social justice understanding of disability, the role of disabled people is critical. The slogan "Nothing about us without us" reflects, firstly, the importance of a unified disability movement and, secondly, the central role of self-representation. It is for this reason that a disability catalyst should pay close attention to the nature and effectiveness of the disability movement as a key sector in bringing about change.

As noted in the historical discussion of the disability movement (see Chapter 4 by Ka Toni & Kathard), engagement with government and political strategising has resulted in huge gains with respect to policy development and political representation of disabled people within the ruling party. However, the lack of success in policy implementation and continuing deprivation of the basic human rights of disabled people (Howell et. al., 2006; Howell, 2006), especially the majority who live in poverty, raises the question of whether these gains have actually served to develop full citizenship for disabled people in South Africa (Dube, 2006). This chapter examines critical issues that need to be considered and relates these to the context of higher education. It also makes suggestions as to how available data and future research can support this process. This discussion is by no means comprehensive or definitive, but rather serves as a starting point for a critical examination of disability activism in the South African context.

CRITICAL ISSUES

A movement that aims to represent all disabled people has a strong obligation to include diversity in its membership. While this is no easy task, it must be taken seriously or the risk exists of further silencing marginalised groups who are represented in name but whose concerns are not reflected (Goodley & Rapley, 2006). This is seen as the starting point for DCA – to acknowledge the diversity within the disability sector. This requires at least three major mind shifts:

- To acknowledge that disability identity is a complex integration of gender, race, class, sexual orientation, age and other positions that disabled people might be placed in or choose to adopt (Shakespeare, 2006).
- To enrich the social model of disability so as to include a consideration of the impact of impairment on the individual (Corker, 2001). For example, people with psychosocial and intellectual disabilities often find that considerations of accessibility do not take into account their specific needs.

- To explore the contribution and influence of the disability movement in mainstreaming disability in policy processes at all levels of governance across different public institutions.

These perspectives run through the critical issues in disability activism and participation identified below, which serve as a starting point for discussion of how activism can be a catalyst for change.

INTERSECTIONALITY

The disability movement has, for obvious reasons of identity and political action, highlighted a disability identity and given minimal recognition to the fact that every person has multiple identities of which disability may be only one (Corker, 2001). Experience in other social movements informs us that the dangers of such an approach are that other forms of difference are submerged and the movement runs the risk of duplicating societal inequalities (such as those based in gender) within the movement. To address this issue seriously, it would be useful to examine the demographics of the membership of disabled people organisations (DPOs) and consider whether these may reflect discriminatory practices within the movement. What recognition is there of difference based on race, gender, HIV and AIDS status, sexual orientation, age (especially children, elderly)? How are specific interests reflected in the operation of the DPO? What are the mechanisms for including a diversity of views under a broad umbrella of disability rights? Such an examination reaches beyond the confines of disability and begins to inform other social groupings so that we begin to learn more about the broad notion of social justice from disability.

SELF-REPRESENTATION

The emphasis placed on self-representation within the disability movement is problematic at two levels. Firstly, self-representation has less relevance within non-Western philosophies of care and community. The notion of the individual as autonomous and independent of their family or household is foreign in many African communities. In such settings, it may be that the disabled individual cannot speak only for his or her own needs and, conversely, the household representative is expected to speak for that disabled individual.

Secondly, recognition of the effects of different types of impairment on self-representation should be considered. This has been largely overlooked because the disability rights movement has highlighted the common experience of social oppression of disabled people, overshadowing the differences implicit in different types of impairment. However, a denial of impairment serves to silence certain groups who need extensive support in order to participate, among them people who are not able to communicate clearly – those with psychosocial and intellectual disabilities, communication impairments and severe to profound physical impairments (Epp, 1999). Self-representation needs to be supported and may take different forms among those with profound intellectual disability or severe multiple impairments. The accessibility requirements of this group need to be taken seriously as they may require information to be made accessible through various means such as less complex language, South African Sign Language or the assistance of a support person. An exploration of the barriers and facilitators to participation for these groups would be useful and this should include a critical look at how they may gain effective representation.

DISABLED CHILDREN AND THEIR PARENTS

Children, whether disabled or not, are the responsibility of their parents. However, many parents feel that this responsibility takes on a different character when their child is disabled (Mckenzie & Müller, 2006). On the one hand, their parenting can be undermined by the assumption of superior expert knowledge on the part of health practitioners and, on the other, they have to fight for services that are readily available for their non-disabled children (e.g. education, health care). The role of parents' organisations is therefore a central question for the disability movement. Are parents genuinely considered full members of the disability rights movement and if not, why not? In general, parents' organisations have been strong advocates for disability rights, especially with regard to education and social development. Parents have had to be resourceful and resilient in raising their disabled children in a frequently hostile environment (Gara, 2007). Despite this overall picture, it is not always the case that parents are the best advocates for their children. Stories of parental abuse, on the one hand, and overprotection on the other, form part of the disability discourse in South Africa.

It is also abundantly clear within the South African context that children

are not always in the care of parents and that there is a vast diversity of families and caregivers that exist with or without parent-led caring. These arrangements must be identified, acknowledged and supported, taking into account the caregivers' perspectives and needs.

DISABILITY RIGHTS AND COMMUNITY EMPOWERMENT

The questions to be asked here include: How can a disability movement engage at a community level, given that poverty and disability are so interrelated, to solve community problems? This has to do with the mainstreaming of disability at a local level into community issues. The inclusion of disabled people and their families in community structures is critical and these structures should consciously encourage such participation. The disability grant is an issue that needs to be examined with respect to the specific benefits to the disabled person and the community. While it is generally agreed that the disability grant supports rural communities (Nattrass, 2007), does it do this at the expense of the personal development of disabled people? If so, how can poverty alleviation be separated from disability?

REPRESENTATION IN PUBLIC OFFICE

The disability rights movement in South Africa has been strategic in using political power to fight for the rights of disabled people. Thus there are many disabled people in public office through proportional representation, through constituency election at local government level or represented on statutory bodies. The question is: How can public office contribute to achieving human rights and what are the challenges of such an approach?

The emphasis in this regard has been self-representation, that is the election of disabled people as a means to having disabled people's concerns heard. However, a more critical approach is called for where the disability movement is clear about what they require from public representatives so as to lobby political parties to adopt this agenda, particularly since proportional representation allows the party to choose the candidates who can support this agenda. In this way disabled candidates have a mandate from the political party that supports disability rights rather than a possible conflict of interest between party politics and disability politics.

The assumption that having a disability fits an individual to represent disabled people needs to be examined at two levels. Firstly, which "selves" are being represented? Disability is not an uncomplicated identity that can be represented in one individual. Secondly, the role of non-disabled people cannot be dismissed. It is possible that a non-disabled person could be a better representative in terms of achieving change and delivery of services. These issues have been insufficiently explored and disabled people need to give serious consideration to what they require from their representatives to enhance their citizenship and participation. DPOs need to draw on research and policy initiatives to understand the impact of policy and practice on disabled people, make their own proposals and lobby for these using their voting power as a lever for change.

DISABILITY LEADERSHIP

Within DPOs, as within any developing organisation, it is necessary to nurture and maintain leadership, especially when the very survival of these organisations is continually under threat. The experience of recognised leaders within the sector needs to be considered as a starting point. What have they been able to achieve and what have been their constraints? At the same time, a review of leadership development and succession practices in the sector would give direction to processes of renewal of energy and dynamism that organisations require from time to time. It seems apt that disability activists look to other social movements for leadership strategies that are effective in building the movement. Political representation is also relevant here and political parties can be called to account on how they are building disability leadership within their ranks.

ENGAGEMENT IN POLICY DEVELOPMENT AND MONITORING

As noted above, the disability movement has been successful in developing disability-friendly policy. The problem that remains is that there is a gap between policy and implementation. This requires that those responsible for implementing policy should be held accountable and their performance monitored. The first entry point to ensure that policies and services are inclusive is at the planning stage. To influence these it needs participation of competent people with disabilities. However, even where people with disabilities are invited, they do not always have the capacity

to participate effectively. What factors contribute to this? Are DPOs managed using sound management principles such as human resource development, and effective and efficient structures with proper planning, implementation and monitoring and evaluation systems? What systems are developed to attract people with the required competence into the organisation?

Further issues that need to be explored are the relationship of the disability movement to government and civil society. Is there a sufficiently critical and independent stance adopted with regard to government performance and delivery to its disabled citizens? Which civil society partners can assist in monitoring policy implementation?

USE OF RESEARCH EVIDENCE AND DATA FOR ADVOCACY

To lobby and advocate, disability activists need to be equipped with information that is accurate and guides decision-making. Within an emancipatory research approach, it is disabled people who need to take the initiative in seeing that this happens. It is here that they need to build relationships with institutions of higher learning to participate fully in the research process and to be able to make use of the products of research. The nature of DPOs' relationships with institutions of higher education, and how these are formalised, must be critically examined. This would include consideration of how the products of these relationships are used in support of advancing the citizenship of disabled people, for example in advocacy campaigns and training courses.

A partnership between a higher education institution and a DPO must be considered as a two-way reciprocal relationship. Inasmuch as a DPO benefits from research expertise, so the institution benefits from learning about the lived experience of disabled people and the perspective of the marginalised citizen. Following on from this insight it would be relevant to ask whether disability is a consideration in all aspects of the work of the higher education institution, in the curriculum across all faculties? Such a consideration has the potential to foster a genuine concern with developing inclusive practices that address a wide range of human diversity, including and beyond disability.

ROLE OF INSTITUTIONS OF HIGHER LEARNING

The development of leadership is a central concern for any institution of higher learning. The institution should be inclusive of disabled people and this entails a consideration of admission requirements, accessibility and course offerings. The inclusion of disability as an issue of diversity on a par with race, gender, sexuality and other dimensions of diversity can enrich an understanding of how difference is construed in our society, contribute to theory and inform practice on issues of social justice. To achieve this, all students should be provided with opportunities to engage with disability issues through their curriculum and to highlight it as an issue of diversity and social justice.

There is a clear role for higher education institutions in research. To engender research that is inclusive of disabled people's concerns, it is important that disability be an integral issue in curriculum development in all faculties and departments. There is a need for research that focuses on citizenship and disability rather than health-related issues alone. Furthermore, it is important that higher education institutions collaborate with and support DPOs in research on disability issues. An outcome would be knowledge production based on African perspectives, and the generation of new theories of disability and inclusive policy processes. These are exciting prospects that have potential to reap reciprocal benefits for all stakeholders.

REFERENCES

Corker, M. (2001) "Sensing disability" in *Hypatia* 16(4):35–52.

Dube, A. (2006) "The role and effectiveness of disability legislation in South Africa" in B. Albert (ed.) *In and out of the mainstream: lessons from research on disability and development*, Leeds: The Disability Press, pp 119–34.

Epp, T.D. (1999) "People First: Voicing disability, embodied identity and social policy in Ontario", PhD dissertation, Department of Social Anthropology, Toronto: York University.

Gara, N. (2007) "Effects of caring on mothers of intellectually disabled children in Alice, Eastern Cape, South Africa", MPhil dissertation, Cape Town: University of Cape Town.

Goodley, D. & Rapley, M. (2006) "Changing the subject: Postmodernity and people with 'learning difficulties'" in M. Corker & T. Shakespeare (eds), *Disability/ Postmodernity*, London: Continuum, pp. 127–42.

Howell, C. (2006) "Changing public and professional discourse" in P. Engelbrecht & L. Green (eds) *Responding to the challenges of inclusive education in southern Africa*, Pretoria: Van Schaik, pp. 82–8.

Howell, C., Chalklen, S. & Alberts, T. (2006) "A history of the disability rights movement in South Africa" in B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider & M. Preistley (eds), *Disability and Social Change: A South African agenda,* Cape Town: HSRC Press, pp. 46–84.

Mckenzie, J. & Müller, B. (2006) "Parents and therapists: Dilemmas in partnership" in B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider & M. Preistley (eds), *Disability and Social Change: A South African agenda,* Cape Town: HSRC Press, pp. 311–23.

Nattrass, N. (2007) "Disability and welfare in South Africa's era of unemployment" in S. Buhlungu, J. Daniel, R. Southall & J. Lutchman (eds) *State of the Nation: South Africa 2007*, Cape Town: Human Sciences Research Council, pp. 179–200.

Shakespeare, T. (2006) *Disability rights and wrongs*, London: Routledge.

Chapter 4

**MZOLISI KA TONI &
HARSHA KATHARD**

WE HAVEN'T ARRIVED:

NO TIME FOR

COMPLACENCY!

This chapter traces some of the historical events that have shaped disability transformation in southern Africa through the actions of the disability movement. It argues that, despite several socio–political gains, the lives of the majority of disabled people have not improved. While political transformation has provided the momentum for disability to be part of the unfolding liberation and democratisation processes in southern Africa, the disability movement cannot become complacent about the significant gains that have been made. Sustained and progressive activism is needed to make the realisation of the ideals of the United Nations' Convention on the Rights of Persons with Disabilities (CPRD) a reality in the wider African context.

HISTORY REVISITED

The situation of disabled people in South Africa before 1994, under apartheid, was characterised by racially segregated services and policies. During apartheid, the South African government offered financial and structural support to service provider organisations such as the Association of Physically Disabled People and the South African Federation for Mental Health. In the absence of organised representation, disabled people were excluded from decision making at multiple levels. Their voice was absent in government structures, service organisations and within their communities. Being marginalised created a situation of hopelessness and voicelessness, which a few disabled people found unacceptable. An activist voice started to emerge that was located in a bigger conversation that began in the United States and the United Kingdom in 1960, which together with the southern African disability rights movement culminated in the formation of Disabled People International (DPI) in the mid–1980s.

Mobilising a regional voice began through the Zimbabwe-based Southern African Federation of Disabled (SAFOD), which was instrumental in motivating the South African disability movement to coalesce into an organised structure (Disabled People South Africa (DPSA)). The disability sector anticipated that Zimbabwe's independence in 1980 would lead to greater alignment with international guidelines for the citizenship of disabled people. The South African disability movement learned from the Zimbabwean experience. Instead of waiting for the disability agenda to be driven by government, they made government the starting point of activism. Getting disabled people into government meant lobbying for an upfront position on disability in South Africa's Office of the President in the newly constituted democratic government. The purpose of

this positioning was to advance the goals of disability inclusion as part of creating an inclusive, non-racial society. A key force in the transformation of disability in South Africa was the ideological support of the international disability rights movement.

POSITIONING FOR INFLUENCE

After South Africa's first democratic elections in 1994, DPSA – as the national disability movement – approached the Minister without Portfolio in the Deputy President's Office, Jay Naidoo, with a proposal to integrate disability in all policies across all public sectors. Naidoo was able to drive this agenda as head of the Reconstruction and Development Programme. The outcome of this visionary proposal was significant. The White Paper on an Integrated National Disability Strategy (INDS) was formulated as a policy for disability integration. The INDS was informed by the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. Underpinned by a human rights philosophy, the INDS became a foundational document for policy development with the aim of ensuring that due attention is paid to disability in the national development agenda.

INCLUSIVE AND REPRESENTATIVE POLICY DESIGN

Hailed as one of the most progressive in the world, the South African Constitution took effect in 1997, providing the benchmark for law, governance and policy development. The design and adoption of the INDS was a significant historical process that demonstrated the mobilising and conscientising effect of inclusive and representative policy design. Public hearings were held across communities in South Africa creating opportunities for multiple stakeholders to find and exercise their voice. Public debate focused on a range of issues that eventually became represented in the INDS as critical concerns of people with disabilities in a developing democracy. The policy-making process was a new experience for the public who were largely unaware of the tedious and complex steps involved in drafting many versions of a Green Paper before it is ratified by Parliament as policy in a White Paper.

BUILDING ALLIANCES

The design of the INDS served a catalytic function in developing the skills base of the disability movement in policy processes and politics. Multiple fissures existed along historical ideological divides, for example there was disagreement among disability partners about the power base created by different strategic alliances. Which alliance(s) would provide the power base for promoting the implementation of disability-inclusive policies? DPSA believed that this could be achieved by aligning itself strategically to the ruling African National Congress (ANC), whose manifesto endorsed mass democratic views. Other disability organisations saw the DPSA alliance with party politics as weakening the collective bargaining power of DPOs. It was argued that the DPOs would not be able to challenge an ANC-led government if they were seen to be part of the regime. However, the view of DPSA was that the political rhetoric was promoting a more inclusive, equitable society. As a result, there were confusing messages sent to government by DPOs and organisations that provided services for disabled people.

EXPOSING HISTORICAL DIVIDES

There were internal divides within disability constituencies and organisations, which were themselves unequal. The well-resourced, largely white, professional-led organisations were inclined to be biomedical and charitable in their orientation to disability. The disability movement, in contrast, consisted of mostly black lay people who had fewer skills but were promoting a rights-based approach. The voice of the disability constituencies was divided by mistrust and suspicion, which did not allow for collective joint action on disability. As a result, the DPOs were hardly able to influence the government. In an attempt to improve this, the South African Federal Council on Disability (SAFCD) was created to coordinate the work of the organisations of disabled people and organisations for persons with disabilities in terms of how they engaged with government.

The problem with the federation was that there were serious unresolved issues because one group came from an impairment-based orientation – deafness, blindness, epilepsy – while DPSA was interested in equalising opportunities, regardless of impairment. This remains a fundamental division. DCA must raise awareness of these issues and provide a forum for debating ways to collaborate and form strategic alliances among different

disability groupings, non–disability movements and higher education institutions. There is a need for multiple platforms to debate and unravel the different interests and understandings.

SAFCD should have allowed a broader representation of disability. While impairment is important, it should not be the overriding factor that serves the interests of some more than others. The impairment focus runs the risk of creating further marginalisation when all impairments are not considered equal. People with less visible impairments such as communication, intellectual and psychosocial impairments are most disenfranchised, even within the disability sector. There is a need, therefore, to consider very seriously how to provide a more united perspective. Our weak links make the disability sector vulnerable because there is no firm unified position or strategy. The argument over terminology in the disability sector, such as whether to talk about "disabled people" or "people with disabilities", is evidence that there is no consensus and the leadership suffers as a result.

After 2000, DPSA realised that it did not have capacity to drive the initiatives and to articulate disability in a convincing way. It therefore took a decision to create new partnerships with higher education institutions and research institutions. The goals were to enhance scholarship and research in disability. This saw the development of the Disability Studies programme at the University of Cape Town, alongside research in aspects of disability, poverty and HIV, working with international institutions. However, despite this gain, a weak link continues to exist as limited funding led to the closure of SAFCD. DPSA is seen as privileged when they meet government or organisations such as the National Economic Development and Labour Council (Nedlac).

Understanding the nature of the problem of partnerships between organisations *of* and *for* disabled people, DPSA lobbied individual organisations to form the South African Disability Alliance (SADA), which would operate in a similar way to the International Disability Alliance (IDA). These organisations come together in the alliance to negotiate issues in the CRPD. SADA has the mandate to oversee 13 organisations. The issues of power and privilege within the different disability organisations and other social partners need to be vigorously debated and monitored so that accountability becomes a vehicle for active citizenship.

Ratification of the CRPD

The South African government, as a signatory to the CRPD, has created a Ministry for Women, Children and Persons with Disabilities. While the formation of this ministry has been contested and its efficiency questioned, SADA nevertheless has the responsibility to monitor the ministry and to hold it accountable, particularly with regard to the implementation of the CRPD. While South Africa has signed the Convention, it is only when implementation takes place that the benefits will be tangible. Achieving the goal of equalisation of opportunity for disabled people is still an aspiration. The Convention speaks to an ideal and the implementation is far from satisfactory. Complacency seems to permeate all structures and levels of government.

Advocating for change

DCA is well positioned to play a role in reminding people what is being taken for granted. It intends to foreground successes and points of contention that, if addressed, could shape a different social history for future generations, especially the majority of disabled people who live in poverty. We require sustainable development that results in meaningful, long-term changes that make practical differences in the lives of disabled people.

Conclusion

There is a belief that things happen if you have a vibrant structure. We have disability structures and disabled people who are in positions of power. It is hoped that this chapter will help foster constructive debate within the disability movement and its social partners, which could lead to appropriate positioning of disability in South Africa. The CRPD presents the region with fresh impetus for renewed efforts to advance the disability agenda. South Africa needs a vibrant disability movement to be the catalyst in this process, holding itself, government, higher education institutions and other social and business parties to account. At this juncture, we encourage engagement with the following questions:

• How do current initiatives benefit disabled people?

- How does the disability movement monitor itself and hold its members accountable?
- How can the collective (disability movements, academic, professional and social partners) move beyond rhetoric and chart tangible and sustainable futures for disabled people in South Africa?
- How can the inclusion of disabled people become part of the development agenda in South Africa?
- Has the voice of the disability movement been elevated to where it can be heard?

Chapter 5

**MADELEINE DUNCAN,
KATE SHERRY &
RUTH WATSON**

DISABILITY AND RURALITY

The implications of fragmented policy implementation for people with disabilities living in rural areas of South Africa is gaining attention as the government prioritises rural development (DPSA, 2009). This chapter is based on a study which is investigating how disability policies in the health, education and social development sectors are understood and implemented by service providers and service users in deep rural villages in South Africa's Eastern Cape province. Critical issues related to service delivery and policy implementation will be raised and questions that might help to stimulate dialogue and bring about change are suggested.

DEFINING RURALITY

Rurality is more than a geographical concept. It refers to the structure, state and quality of life of people living in sparsely settled places away from the direct influence of large cities and towns. Human settlements are considered rural when more than 50% of people live at least five kilometres from a tarred road and more than 25% of residents use water from streams, rivers, dams or rainwater tanks and have limited choice or access to public services (RuDASA, 2006). People with disabilities who live in isolated rural areas face a unique set of participation restrictions associated with their geo-social positioning. Overcoming the limitations associated with impairments is particularly difficult in an underdeveloped, resource constrained and geographically isolated location. The terrain people have to traverse and the vast distances they have to travel to access resources and services add to the cost burden of disability in rural areas.

POLICY FRAMEWORKS

A policy, as an organised set of values, principles and objectives, is formulated as a framework to guide the actions of service providers and service users. National policy is implemented through a system of committees and structures of government that are constituted at national, provincial, district and local government (municipal/mayoral/ward) levels (Sicelo, 2009). The effective implementation of a policy depends on service providers at every level of government as well as citizens as public service users being informed about its content, capacitated for its implementation and committed to its objectives. South Africa has comprehensive and inclusively formulated policies that address the needs of special groups of people including people with disabilities (DPSA, 2009), but at present

implementation falls far short of intended outcomes. Poor policy implementation is a universal phenomenon that occurs because governments create policies as a symbolic gesture with the caveat of progressive realisation (Alant et.al., 2007). Effective implementation requires the political will to promote efficient multi-sectoral collaboration. Service delivery is a multi-directional process requiring interaction between governance and community structures that are capacitated and accountable in the distribution, deployment and utilisation of resources. In short, both service providers and service users must be policy literate for effective policy implementation to occur.

INTENTION OF DISABILITY POLICY

The intention of disability policy is to bring about progressive social change that promotes universal access to resources and opportunities for people with disabilities to participate in society. Achieving the intentions of disability policies will, however, benefit all citizens because a barrier-free society promotes social justice. Swartz & Schneider (2006:235) suggest that "in the social model of disability we can, in fact, decrease the prevalence of disability by changing the environment – physical and/or attitudinal". The lives of disabled people and their households are considerably compromised in rural areas where the pre-conditions for policy implementation are difficult to orchestrate. Achieving robust levels of disability policy implementation is hampered by geographical isolation, structural underdevelopment and other pressing social problems such as unemployment and food insecurity. About two-thirds of the country's poor people live in rural areas and more than two-thirds of rural people are poor (Department of Agriculture, 2006; Francis, 2006). Poverty and disability are inextricably linked (Yeo & Moore, 2003; Palmer, 2011), which is why rural policy cannot attempt to address the one without the other. According to Gilson & Erasmus (2008:1) "… experience shows that it can be more difficult to deal with the political and institutional barriers to implementation than to design new policies and programmes. Predicting and managing these political and institutional factors is essential to make the [desired][1] changes…". When policy attempts to change the status quo and promotes the cause of powerless people, but does not factor in accountability for service provision, or has high expectations of community participation, the effectiveness of implementation will be challenged (Gilson & Erasmus, 2008).

CASE STUDY OF A RURAL VILLAGE IN THE EASTERN CAPE

The rural area chosen to illustrate these issues lies within the Mount Frere Municipality of the Alfred Nzo District, Eastern Cape. It includes an estimated 100 000 rural inhabitants (StatsSA, 2006) and is shaped by remoteness, underdevelopment, de-agrarianisation and adverse incorporation (Du Toit & Neves, 2007). An instrumental case study was launched in 2010 with the cooperation of purposefully sampled service providers from the departments of Education, Health and Social Development (Sherry, 2011). The aim of the study, using semi-structured interviews, was to explore participants' knowledge and experiences with the implementation of policies that pertain to the needs and rights of people with disabilities who live in remote rural villages within the district. Interviewees were working in mainstream public sector services and special service units. Logistically it was not possible to achieve data saturation, but major issues that emerged pertain to the training of service providers in policy implementation, the conceptualisation of what 'disability' means and management directives that determine which services are provided and how delivery is interpreted (Sherry, 2011). The perspectives of service users, gathered through a range of participatory rural appraisal methods, will be reported elsewhere (Booi, 2012). A brief summary of the findings from service provider interviews follows.

Policy training

Policy documents are distributed via the provincial service authorities to district level. The guidance of policy implementation between the service sectors was not uniform. Officials in the departments of Education and Health were expected to read and interpret documents on their own and without training, but within the framework of the specific department's general guidelines and priorities. Social workers reported some training, but this was not formalised or consistently presented. They also referred to the policy/guiding principles for their national department, which they are required to adhere to. During the interviews it emerged that understanding of the policy documents was dependent on each official's familiarity with document analysis, with the English language (which is used for all policy documents), the interpretation of the meaning of disability, and with the services that the respective departments were able to offer. Some people admitted that they were not familiar with the relevant policy and therefore took their instructions from superiors. Cross-sector

collaboration was almost non-existent. Service providers, responsible for the interpretation of the same policy and for disability and/or rehabilitation portfolios within their departments, were unaware of their official counterparts in each of the other sectors or of the mechanisms through which services were being implemented.

Conceptualisation of disability

The Department of Social Development is tasked with providing social clubs and some form of "occupation" for their clients. A group of interviewees appealed to the researchers to help them find a container to house the group of disabled people whom they wanted to serve. Well meaning but misguided attitudes illustrated a lack of appreciation not only of the needs and rights of disabled people, but also a misinterpretation of what disability means. According to Anon (1994:707) attitudinal mechanisms "exclude many groups from the market itself and from public goods and services. An alternative to disengagement and passive, compensatory policies would be to design proactive social policies based on an understanding of the mechanisms of exclusion". The politics of disability and the role of disabled people's organisations as partners with the public sector in service delivery did not feature in the interviews.

Service directives

Services generally appear to be dictated by local needs and specific national priorities, e.g. HIV and AIDS awareness and treatment campaigns, and the provision of social grants. Social security grants offer people with disabilities and other vulnerable groups some form of protection via financial assistance (Patel, 2005). A disabled individual may not achieve financial security via the grant system if this income is the only source of provision for the household. Depending on the specific needs and ingenuity of its members, each household will try to manage its resources through various forms of entrepreneurship. However, a disability grant holder is excluded from earning an income (beyond a very minimal amount). Interpreting directives for identifying who qualified for or when to stop a disability grant was particularly problematic. In other instances, service providers designated to provide specific services to disabled people, e.g. inclusive education, responded to the pressure of public need rather than the intention of policy. For example, there is a great demand for placement of children with special intellectual needs in the only full-time care facility in the research study district. Time and attention was therefore diverted to meet the needs of this special group with no consideration of other categories of disability. None of the people interviewed were able to report on the

inclusion of disabled children in mainstream schools in the study district. This raises questions about the understanding that directors have about disability, given that intellectual disability was the only disability-related service the interviewees referred to.

WHY DOES DISABILITY POLICY CONTINUE TO MISS ITS MARK?

Policies that seek to promote equity and social justice are particularly diffi-cult to implement because, in seeking to benefit powerless groups, they challenge the status quo and associated vested interests. Critical issues that arise from this question include the following:

- People with disabilities continue to be marginalised and misunder-stood in our society. For example:

    - Respect for human differences is not valued.

    - Terms used to describe disability are derogatory.

    - Government policies are interpreted by service providers in terms of what can be done to deal with the "problem", and not how people, who have equal rights (but are different, as we all are), can be helped to realise full citizenship.

- The implications of a neoliberal philosophy[2] (Desai & Maharaj, 2010) for people who are very poor and disabled are not accounted for in disability policies. For example:

    - The anticipated benefit from the so-called first economy is not trickling down to the second, i.e. although people with disabilities living on the margins of society are supported by social security, they have limited development opportunities to lift themselves out of poverty.

- While the intention of disability-related policy is to bring about change, the rights and responsibilities of disabled people cannot become a reality as long as neither their equality nor equity is realised across all sectors, including higher education. For example:
- Political and institutional factors that influence disability policy implementation are not being addressed in higher education curricula responsible for training future service providers.

What would make a difference?

Policy implementation will be facilitated when responsibility is assumed by all stakeholders. Working together, both service providers and ordinary citizens, including people with disabilities, need to challenge social exclusion and discrimination. The disability agenda is, in effect, a national transformation agenda. Let the debate of how to bring about the desired changes continue, especially through the youth, our hope for the future.

Critical questions for dialogue

- Who is responsible for building the capacity of government structures and service providers to enable implementation of policies that are inclusive of disability?
- What is the best way of doing this in rural areas?
- How can different levels of government be held accountable to each other and to the disability movement?
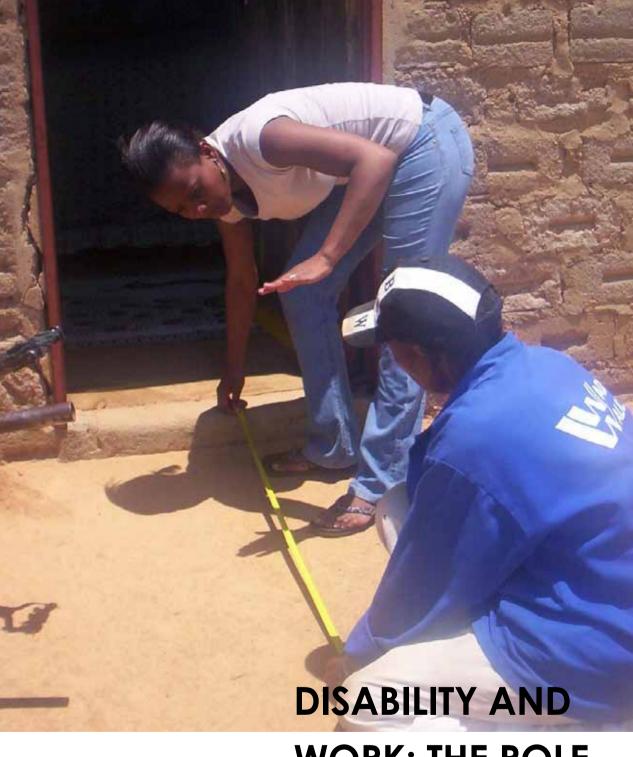
Endnotes

1   Author's insert

2   South Africa's macro-economic policy and the neoliberal privileges granted to the corporate sector mean that the anticipated trickle down to the so-called second economy is not happening, nor can it until the way that the first economy operates changes (Desai & Maharaj, 2010: 39).

References

Alant E, Emmett A, Samuels A. "Disability stakeholders' perspectives regarding social development" *South Africa Journal of Occupational Therapy*, 2007, 37:3, p. 34-38.

Anon. Social exclusion: a concept for the world summit for social development.

Booi M. Service delivery and disability: the perspectives of service users on socio-economic rights in a rural community in the Eastern Cape. Unpublished M.Phil (Disability Studies) thesis (in progress), Division of Disability Studies, Department of Health and Rehabilitation Sciences, University of Cape Town.

Department of Agriculture, South Africa. Food insecurity in Sekhukhune. http://www.fanrpan.org/documents/d00498/FIVIMS_Info_Brief1_Food_insecurity_Sekhukhune.pdf

Department of Education. Education White Paper 6: Special needs education – Building an inclusive education and training system, Pretoria: Department of Education, 2001, http://www.polity.org.za/html/govdocs/white_papers/educ6.html.

Department of International Development: DFID. Disability, poverty and development,
     policy paper, Disability knowledge and research programme (KaR), 2000.

Desai A, Maharaj B. "Debating the first and the second economy" in Maharaj B, Desai
     A, Bond P, *Zuma's own goal. Losing South Africa's 'War on Poverty'*, Trenton, NJ:
     Africa World Press, 2010, p. 37–57.

Disabled People South Africa (DPSA). *Pocket guide to disability equity: an empowerment tool*.
     DPSA Parliamentary Office: Cape Town, 2009.

Du Toit A, Neves D. *In search of South Africa's second economy: Chronic poverty, economic
     marginalisation and adverse incorporation in Mount Frere and Khayelitsha*, Chronic
     Poverty Research Centre Working Paper 107, Programme for Land and Agrarian
     Studies, School of Governance, University of Western Cape, 2007.

Ferguson J. "Rethinking poverty and assistance in South Africa" in Maharaj B, Desai A,
     Bond P, *Zuma's own goal. Losing South Africa's 'War on Poverty'*, Trenton, NJ: Africa
     World Press, 2010, p. 399-416.

Francis E. *Poverty: causes, responses and consequences in rural South Africa*, Development
     Studies Institute (DESTIN), London School of Economics, London, 2006.

Gilson L, Erasmus E. *Tackling implementation gaps through health policy analysis*, Equinet
     Policy series, Regional Network for Equity in Health in East and Southern
     Africa, co-published by Equinet and Centre for Health Policy, University of
     Witwatersrand and Health Economics Unit, University of Cape Town, Series no.
     21, September 2008, http://www.equinetafrica.org

International Labour Review 133(5-6):701-707. Available as an e-journal article through
     the John Rylands Library, University of Manchester, accessed 23 November 2010.

Office of the Deputy President (ODP). White Paper on an Integrated National
     Disability Strategy, 1997.

Palmer M. "Disability and poverty: a conceptual review" in *Journal of Disability Policy
     Studies,* 2011, 21(4), 210-218.

Patel L. *Social welfare and social development in South Africa*, Oxford: Oxford University
     Press, 2005.

Province of the Eastern Cape . Alfred Nzo District Municipality, Social Development
     and Special Programmes, http://bit.ly/vEyqoC, accessed 20 October 2011.

Rural Doctors Assocation of Southern Africa (RuDASA). Position paper: A rural health
     strategy for South Africa, 2006, p. 5, www.rudasa.org.za

Sherry K. Critical interfaces: Implementation of disability policy in health, education &
     social development in the villages of Mpoza, Eastern Cape, unpublished Phase1
     research report, People in forming Policy: Power & Progress, SANPAD project
     09/25, Division of Occupational Therapy, School of Health & Rehabilitation
     Sciences, University of Cape Town, 2011.

Sicelo S. Speech delivered by Minister of Cooperative Governance and Traditional
     Affairs, during the process of developing a White Paper on cooperative governance
     in South Africa, National Assembly, Parliament, Department of Cooperative
     Governance and Traditional Affairs, Cape Town, South Africa, 2009, http://www.
     info.gov.za/speech/DynamicAction?pageid=461&sid=6130&tid=6275

Swartz L, Schneider M. "Tough choices: Disability and social security in South Africa"
     in Watermeyer B, Swartz L, Lorenzo T, Schneider M, Preistley M (eds.) *Disability
     and Social Change: A South African Agenda*, Cape Town: HSRC Press, 2006.

Yeo R, Moore K. "Including disabled people in poverty reduction work: 'Nothing
     about us without us'" *World Development*, 2003, 31:3, 571-590.

DISABILITY AND WORK: THE ROLE OF HIGHER EDUCATION

Chapter 6

LANA VAN NIEKERK

Participation of people with disabilities in the world of work has been shown to be a human rights issue (Truter, 2009; Bhabha, 2009), thus placing the responsibility for finding solutions within the domain of civil society organisations. This chapter will make the argument that higher education institutions (HEIs) are ideally placed to equip their students (the future leaders of the country) with knowledge, skills and attitudes required to contribute to the creation of an inclusive society. Such a society will offer opportunities for people with disability to participate in the world of work alongside their non-disabled counterparts. The creation of an inclusive society will require its citizens to possess, at the very least, a set of basic competencies to contribute to disability equity.

Kane's (1992) definition for competencies as cited by Lysaght & Altshuld (2000) will be used here, namely, "the capacity of individuals in a partic-ular position to apply knowledge and skills in an effective manner in the full range of situations associated with that position". Importantly, competencies are seen to include personal attributes such as values, beliefs, attitudes and judgement.

The role of higher education in producing such citizens has not received serious consideration. While social responsibility recently surfaced as a generic outcome of HEI programmes, disability has not received any such consideration. The specific focus of this chapter is an exploration of the key disability competencies required by South African citizens for them to contribute to equal opportunities for people with disabilities in work – as part of an inclusive society.

All students enrolled in HEIs are being prepared for entry into the world of work. Graduate profiles that are drawn up to guide curriculum devel-opment often include social responsiveness as an explicit exit competency, thus, the stage is set for refining such competence to include disability competencies. The argument is thus that each student, on graduation, should have at least the basic competence to participate in an inclusive society in which people with disabilities are co-workers, employees and employers. Without such competence, the tendency will be for them to (knowingly or unknowingly) restrict the participation of people with disabilities in regular work environments.

The interests of people with disabilities are most acutely affected in the social and economic arena; they are most vulnerable in employment, health, education and social services – all areas of life which "cut to the core of a person's being in the world and one's potential to live a mean-ingful life" (Bhabha, 2009).

Disability is one of the key factors identified in the Employment Equity Act No. 55 of 1998 to receive redress, yet no significant attempt has been made to develop a society in which people with disabilities are equal participants in the world of work. The ideal situation will be for all graduates to possess a level of disability awareness needed to promote opportunities for people with disabilities. At the very least they should be able to recognise negative stereotypes causing stigma and endeavour to work against these. HEIs are ideally positioned to counteract the perpetuation of myths associated with disability that continue to hamper processes through which people with disabilities find work. According to a recent Employment Equity report (Department of Labour, 2009/2010) only 0.9% of the total number of employees (that were reported on) were people with disabilities. The private sector was reported to be doing slightly better (1%) than the government sector (0.6%). A clear strategy with emphasis on work equity for disabled people is required.

The precedent has been set for grand scale education of South Africans to address urgent concerns, for example, the inclusion of HIV/AIDS education as part of the Life Skills curriculum in schools and most HEIs.

Students enrolled in particular programmes – those that require specific knowledge of disability to provide specialist disability services - will obviously require a more sophisticated set of competencies. The interrelatedness of disability and identity has been shown to impact on people with psychiatric disability in their quest to participate in the world of work (Van Niekerk, 2005). This interrelatedness is an important consideration given the fact that participation in work has been found to be a source of wellness for people with psychiatric disability who manage their identities through participation in it (Van Niekerk, 2009). A review of recent literature was conducted to paint a picture of disability competencies identified to be useful. A number of studies explored the competencies service providers required to work within mental health services, but very few investigated disability competencies – and none were done in South Africa.

Gardner et. al. (2010) explored the competencies (knowledge, skills and attitudes) required by coordinators to achieve optimal return-to-work outcomes for injured workers in a qualitative study. Interview data were analysed through a process called affinity mapping. Interestingly, most of the competencies identified by Gardner can be described as generic competencies, including conflict-resolution skills (negotiation skills and the ability to remain neutral or non-judgemental), problem solving (creativity, open-mindedness, being realistic and objective), organisation and administration skills, and communication skills. Knowledge

competencies were more specific to the job at hand, including ergonomics, knowledge of disorders and conditions, aspects of pain and disability, and strategies with which to establish and maintain return-to-work programmes. Similarly, Strike (Strike et. al., 2004) utilised a self-report survey with mental health professionals working in counselling offices, disability services offices and doctoral counselling programmes. Findings identified relatively positive attitudes towards people with disabilities, but a lack of knowledge about specific types of disabilities and the general experience of people with disabilities. Mixed results were found in terms of skills needed to work with people with disabilities.

Louvet (2007) reported on two experimental studies (based in the United States) in which data collected from 284 management undergraduates were analysed to determine social judgement towards job applicants with disabilities. The findings revealed that participants evaluated applicants with disability more negatively than applicants without disability for jobs involving a lot of interpersonal contact (Study 1) and for jobs associated with being male (Study 2). This type of devaluation has been consistently reported and will continue to affect opportunities for people with disabilities unless a strong emphasis is placed on inclusion of disability awareness with a particular focus on work (Louvet, 2007).

A range of studies looked into the competencies of mental health professionals and recommendations have been made. Artman and Daniels (2010) used a cultural competence framework to identify the range of competencies considerations, which, in the South African context, would be understood as reasonable accommodation strategies to make their practice more accessible, for example, building accessibility, consent forms, information (hand-outs and publications), scheduling of appointments, psychotherapy milieu, testing, promotional material (websites, client recruitment, flyers) and advocacy.

Bilsker and Wiseman emphasised the need for psychiatrists to understand the difference between impairment and disability (Bilsker et. al., 2006). This particular knowledge competency is, in my opinion, essential for service providers and citizens who are not directly concerned with facilitation of work opportunities for people with disabilities. Without the ability to make this differentiation, the tendency will be to perpetuate the medical model perspective that is focused on "fixing" people with disabilities to fit a society that is not inclusive in nature.

Critical questions for future issues of DCA focused on employment would be:
• What influence does the medicalisation of employment and

impairment/disability have on people with disabilities?

- What are the significant differences in employment equity related to different impairment categories?

- How do we lobby for reasonable accommodation for people with "hidden" and stigmatised impairment?

- How would different approaches to development affect employment of people with disabilities?

REFERENCES

Artman, L. & Daniels, J. (2010) "Disability and psychotherapy practice: Cultural competence and practical tips" in *Professional Psychology: Research and Practice* 41(5):442-448.

Bhabha, F. (2009) "Disability equality rights in South Africa: Concepts, interpretation and the transformation imperative" in *South African Journal on Human Rights* 25(2):217.

Bilsker, D., Wiseman, S. & Gilbert, M. (2006) "Managing depression–related occupational disability: A pragmatic approach" in *Canadian Journal of Psychiatry* 51:76–83.

Department of Labour, South Africa (2010) *The Commision for Employment Equity Annual Report*.

Gardner, B.T., Pransky, G., Shaw, W.S., Nha Hong, Q. & P. Loisel (2010) "Researcher perspectives on competencies of return–to–work coordinators" in *Disability and Rehabilitation* 32:72–78.

Louvet, E. (2007) "Social judgment toward job applicants with disabilities: Perception of personal qualities and competences" in *Rehabilitation Psychology* 52:297–303.

Lysaght, R.M. & Altshuld, J.W. (2000) "Beyond initial certification: the assessment and maintenance of competency in professions" in *Evaluation and Program Planning* 23:95–104.

Strike, D.L., Skovholt, T.M. & Hummel, T.J. (2004) "Mental health professionals' disability competence: measuring self-awareness, perceived knowledge and perceived skills" in *Rehabilitation Psychology* 49:321–327.

Truter, L. (2009) *Disability: The quest for reform*, Tax and Legal Division, Price Waterhouse Coopers.

Van Niekerk, L. (2005) "Influences impacting on the work-lives of people with psychiatric disability: An interpretive biography", Doctoral dissertation, University of Cape Town.

Van Niekerk, L. (2009) "Participation in work: A source of wellness for people with psychiatric disability" in *Work: A Journal of Prevention, Assessment & Rehabilitation* 32:455–465.

Chapter 7

JUDITH VAN DER VEEN

A STRUCTURAL APPROACH TO MONITORING DISABILITY INCLUSION

Inclusion is about a sense of belonging, about feeling respected, valued for who you are (Miller & Katz, 2002). It is an all-encompassing practice of ensuring that people of differing abilities related to, for example, sex, age and race, feel a sense of belonging, are engaged, and are connected to the goals and objectives of the whole wider society (Jaeger & Bowman, 2005). Disability inclusion is about society changing to accommodate difference and to combat discrimination related to people with disabilities. It requires that disabling barriers are removed and personal needs relating to impairment are met, thus making possible the full involvement of people with disabilities and enabling them to benefit from services on an equal basis with others. Because disability discrimination is not always easily detectable, it is critical to highlight and carry out research into the full spectrum of environmental, institutional and attitudinal barriers that exclude people with disabilities, including programmatic and/or policy choices (Guernsey, et. al., 2006). To highlight the issues, the situation of people with disabilities needs to be made visible.

Currently there is minimal information available about the barriers and discrimination people with disabilities face. This absence of information is due to a lack of clear understanding of disability actions in plans and structures at all levels of government and in organisations. Progress can only be monitored if appropriate indicators to appraise the progress of activities and targets are developed. The monitoring of disability inclusion is hampered by the absence of clear targets and respective indicators, especially in government sectoral plans. Defining these targets and indicators will allow constant data collecting, monitoring and reviewing of progress. In addition, ways to capture unintended outcomes need to be considered.

There is a need to collect information and monitor both disability-inclusive and disability-specific legislation and policies. Disability-inclusive refers to frameworks whereby a disability dimension has been mainstreamed into legislation, policies and programmes. Disability-specific refers to legislation, policies and programmes that focus specifically on people with disabilities or disability issues such as a disability law, a national action plan on disability, or specific sectoral laws and plans such as a law on employment of people with disabilities, laws on social security of people with disabilities, and so on. It is important to know which policies and plans have clear targets and dedicated budgets. This kind of information could be extremely useful for disability activists when lobbying for implementation of policies.

DISABILITY MAINSTREAMING AND EQUAL OPPORTUNITIES

People with disabilities have the right to be included in mainstream society and to participate in family, community and national life. Equal opportunity is defined as the process through which the various systems of society and the environment, such as services, activities, information and documentation, are made available to all (UN, 1992). South Africa has an Integrated National Disability Strategy White Paper (INDS) (ODP, 1997) and has ratified the United Nations' Convention on the Rights of Persons with Disabilities (UN (b), 2007). Mainstreaming is promoted, for example, in the disability framework for local government 2009-2014 in South Africa (DPLG, 2009). What needs to be considered in assessing the structural factors of inclusion is the extent to which structures are put in place to ensure equal opportunities for people with disabilities and to mainstream disability in development programmes.

Mainstreaming is the process of assessing the implications of any planned action, including legislation, policies and programmes, in all areas and at all levels for people with disabilities. It is a strategy for making disabled peoples' concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes across all sectors in all political, economic and societal spheres to avoid perpetuating inequality (adapted from ECOSOC, 1997). A perspective that includes people with disabilities leads to more informed policy options and impacts, and better understanding of formulating policies to narrow the gap between people with and without disabilities.

HOW TO MONITOR STRUCTURAL FACTORS

Very few tools have been developed to promote and measure disability mainstreaming and inclusion such as the EDAMAT tool for effective disability mainstreaming (Leonard Cheshire International, 2006) and a checklist for inclusion (Heinicke-Motsch & Sygall, 2004). Information gained from them has, so far, not been widely shared. Specific aspects and areas that need to be monitored are sectoral mainstreaming, resource budget allocation, participation and accessibility.

SECTORAL MAINSTREAMING

Analysis of mechanisms used to develop, implement and monitor sectoral plans should answer the following questions:

- To what extent are existing sectors and services, such as health, education and social protection, putting programmes in place to facilitate the inclusion of people with disabilities?
- Are there strategies to promote livelihood and work opportunities for people with disabilities (including access to credit)?
- What specific disability targets and indicators are proposed for monitoring and evaluation, and where are they being collected?

Higher education institutions (HEIs) need training on how to ensure the mainstreaming of people with disabilities within all teaching and research activities, particularly in poverty assessments, social exclusion, children and gender studies.

ALLOCATION OF RESOURCES

Budget allocation ringfenced for disability in each sector will facilitate implementation. Disability spending is indicative of a government's commitment to disability matters in general. Analyses of budget allocation and expenditure is, thus, an important area of research for HEIs and research organisations to undertake. Questions to be answered include:

- To what extent have specific budget allocations for disability been made relative to other budget allocations?
- To what extent does disability feature in the national structures for reporting on national budgets?

PARTICIPATION

Participation requires and gives expression to self-determination and empowerment and is an integral part of being a citizen. Participation by people with disabilities in the planning, design, and implementation and monitoring of programmes at family, community and national levels is central to inclusion. Questions include:

- Do families and communities include people with disabilities?

- What are enablers and barriers?
- Are activities structured in a way that promotes participation by people with disabilities on an equal basis with non-disabled peers?

ACCESSIBILITY

Accessibility is a further prerequisite for inclusion. Comprehensive accessibility (also called universal design) ensures that buildings, products, services and information are designed in such a way to be accessible, usable, understandable and comfortable for all people without discrimination (Handicap International, 2008). DCA wants to stimulate further research into this topic through questions such as:

- Have resources been put aside for reasonable accommodation, interpreters, printing in accessible formats, etc.?
- What is the socio-economic impact at individual, household, community and national levels of providing or not providing access in relation to the built environment, products, services and information?

Accessibility needs to be assessed with regards to five components:
- The built environment and physical accessibility (e.g. housing, public buildings, public spaces).
- Geographic location and natural environment (e.g. climate and climate change, natural disasters).
- Provision of assistive devices and technology (e.g. products, technology).
- Attitudinal factors and supportive relationships (e.g. traditional belief systems, cultural and religious systems).
- Services and systems in society (e.g. information and communication, transport, health care services, education services, basic amenities, safety).

INDICATORS OF INCLUSION AND MONITORING SYSTEMS

To measure the progress of societies towards inclusion there needs to be a close link between the design of disability indicators and the questions that they intend to answer. Disability indicators may be developed in two broad ways. Firstly, by disaggregation of standard indicators (e.g.

proportion of children enrolled in primary schools who are disabled). Secondly, by developing disability-specific indicators, (e.g. the number of Grade One English books printed in Braille).

Clear indicators allow us to:

- Establish the extent of inclusion.
- Determine the direction of change over time.
- Assess the impact of programmes and activities undertaken to promote inclusion and determine who is still excluded.

Questions have to be asked about the existing government monitoring systems and what data is already collected systematically at different levels. These questions could include:

- To what extent has data been disaggregated and analysed for disability and where are the gaps?
- Have discussions taken place with the National Bureau of Statistics as well as research units in HEIs and research organisations to assess where further disaggregation and analysis is possible?
- What types of reports are published by government and civil society to highlight disability?
- Would it be possible to extrapolate information from existing reports to highlight disability?
- Which civil society stakeholders collect data in an organised way and to what extent do they include information about disability?

Answers to such questions will be useful as they will provide examples of sectoral targets, indicators and possible means of verification and budget allocation from other countries. Disability indicators are useful only if data are collected on a regular basis, for example, in national census or household surveys by statistical offices.

CONCLUSION

Disabling barriers need to be documented, measured and monitored to determine the extent to which systems and structures meet the needs of people with disabilities. This process should lead to clearly defined activities and targets.

The combination of structural level measurement for monitoring and evaluation complement a more individual focus of measurement described in the next chapter.

REFERENCES

Department for Provincial and Local Government (DPLG), South Africa (2009) *Disability Framework for Local Government 2009–2014*.

Economic and Social Council – United Nations (ECOSOC) (1997) "Gender mainstreaming in the United Nations system", E.1997.L.10.Para.4, adopted by ECOSOC July 1997, http://www.un.org/womenwatch/osagi/pdf/ ECOSOCAC1997.2.PDF, accessed 17 May 2011.

Finkelstein, V. & French, S. (1993) "Towards a psychology of disability" in J. Swain, V. Finkelstein, S. French & M. Oliver (eds), *Disabling barriers – enabling environments*, London: Sage.

Guernsey, K., Nicoli, M. & Ninio, A. (2006) *Making inclusion operational: Legal and institutional resources for World Bank staff on the inclusion of disability issues in investment projects*, World Bank, http://siteresources.worldbank.org/INTLAWJUSTICE/ Resources/LDWP1_Disability.pdf.

Handicap International (2008) *How to build an accessible environment in developing countries*, Handicap International, France.

Handicap International & CBM (2007) *Making PRSP inclusive*, http://www.making-prsp-inclusive.org/en/home.html, accessed 17 May 2011.

Heinicke-Motsch, K. & Sygall, S. (eds) (2004) *Building an inclusive development community: A manual on including people with disabilities in international development programs*, Mobility International, USA.

Jaeger, P. & Bowman, C. (2005) *Understanding disability: inclusion, access, diversity, and civil rights*, Connecticut: Praeger Publishers.

Leonard Cheshire International (2006) *EDAMAT, A practical tool for effective disability mainstreaming in policy and practice*, http://www.lcint.org/?lid=3653, accessed 17 May 2011.

Miller, C. & Albert, B. (2005) *Mainstreaming disability in development: Lessons from gender mainstreaming*, Disability Knowledge and Research programme (Disability KaR).

Miller, F. & Katz, J. (2002) *The Inclusion Breakthrough: Unleashing the real power of diversity*, San Francisco: Berrett-Koehler Publishers.

Office for Disability Issues (2007) *Roadmap 2025, disability equality indicators*, http://odi. dwp.gov.uk/roadmap-to-disability-equality/indicators.php.

Office on the Status of Disabled Persons, South Africa (1997). *Integrated National Disability Strategy – White Paper*.

United Nations (2007a). *Convention on the Rights of Persons with Disabilities and Optional Protocol*, United Nations ENABLE, New York, http://www.un.org/disabilities/ documents/convention/convoptprot-e.pdf, accessed 17 May 2011.

United Nations (2007b) *Convention and Optional Protocol Signatures and Ratifications*, United Nations ENABLE, http://www.un.org/disabilities/countries. asp?navid=12&pid=166, accessed 26 February 2011.

Wikipedia (n.d.) *Inclusion (disability rights)* http://en.wikipedia.org/wiki/Inclusion_ (disability_rights), accessed 17 May 2011.

Chapter 8

MARGUERITE SCHNEIDER

INDIVIDUAL MEASURES FOR MONITORING INCLUSION

Other chapters in this DCA have set out important areas of consideration for people with disabilities and realisation of their rights and full inclusion and mainstreaming. To determine whether inclusion and mainstreaming are being achieved, information or data are required that address change in people's lives. One component of this monitoring and evaluation exercise is collecting statistics at population level (local, district and national levels) – the focus of this chapter. Other complementary components include intensive and in-depth analyses of people's experiences.

Comprehensive understanding of the impact of disability on the lives of individuals and their households requires information at an individual level complemented by information on the structural organisation of a society and the provision of services. This chapter considers the individual and the different measures required to describe that individual and his/her experiences. The preceding chapter presents the broad structural focus and looks at measures to describe various features such as policies, services, the built environment and so on.

Monitoring and evaluation imply measurement of a number of indicators and comparing measurements at different points on a time line. This chapter sets out the critical concerns in what needs to be measured and how it should be measured. As such, it provides support for the other chapters.

To introduce the issue of measurement we need to:
• Understand what aspects require what type of data for monitoring and evaluation. For example, employment status and school attendance lend themselves to individual level data collection; structural aspects such as policies, service provision and other macro level features of the physical and social environment lend themselves more to descriptive information.
• Understand what it is we need to measure – in this case disability and various areas of life discussed in the other chapters.
• Identify components of what we want to measure (e.g. components of disability, employment, education, social inclusion, access to services, etc.).
• Identify existing measures or develop new, effective and tested measures for these components.
• Put the data collected using these measures back into the framework of disability and other areas to evaluate what it is that was targeted for evaluation at the start.
• Integrate individual and structural sources of information into a coherent and comprehensive monitoring and evaluation account.

- Repeat these measures at regular intervals to analyse trends over time to describe changes, both positive and negative.

Understanding disability

The UN's Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006), describes disability as an "evolving concept" resulting "from the interaction between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others" (UN, 2006; Preamble). Article 1 of the CRPD further develops this theme in stating:

> *Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*

The above descriptions highlight the multidimensional and relational nature of disability – there are a number of components included in the description from Article 1, an interaction of these and an outcome – disability. The components of disability, thus, include both individual factors (internal to the individual) and contextual factors (external factors). In addition, the outcome of the interaction can also be measured, for example, as educational level achieved, employment status, access to services, social inclusion (e.g. organisational membership). The structural aspects of communities and neighbourhoods at local, provincial and national level all play a role as factors that determine the level of disadvantage or inclusion experienced by people with disabilities.

The contextual factors (also referred to as environmental factors) can be grouped into immediate or macro, community or meso, and broad or micro level factors. The micro and meso environments are those factors that have a direct impact on the individual on a daily basis. These would include assistive technology, accessibility of the built and natural environment, support and attitudes of family, friends and service providers, and cultural beliefs and practices within the person's social community and geographical neighbourhood. The macro environment includes aspects such as national legislation and policies and the systems that implement these through services. (Schneider et. al., 2003).

The broader aspects (some meso and most macro level factors) can be assessed in relation to an individual's daily experience (e.g. a social

assistance policy and specified eligibility criteria in terms of an individual's eligibility) but also at a generic or structural level (presence or not of policies and inclusion of disabled people within these policies). While there is some overlap between the individual and broader factors (e.g. accessibility of buildings), it is useful, for measurement purposes, to divide them into individual and structural factors. Individual measures would relate to measures of the individual and his or her interaction with the external environment, while structural measures would be more generic measures of basic requirements for an inclusive environment. For example, the accessibility of buildings, provision of services, through to national policies and general attitudes can all be measured independently of the individual to ensure that there is a basic level of inclusion present in any society. This chapter discusses individual measures.

INDIVIDUAL MEASURES

Individual measures describe the internal factors of an individual as well as some of the more common micro and meso environmental factors. The internal factors include age, sex, language and/or ethnic group, educational level reached, employment status, personality traits and coping styles, and, crucially, functional status. All except for functional status and coping styles/personality traits are common measures and do not require further elaboration here. Personality traits and coping styles are complex and difficult to measure, but there are a number of personality trait assessment tools in the field of personality theory in Psychology. However, they remain complex assessments requiring skilled administrators.

Functional status refers to the person's ability to do various activities required or desired for daily living. These include basic activities such as walking, seeing, hearing, remembering, concentrating and communication, through to the more complex activities of maintaining employment, social interactions, attending school and benefiting from education, and so on. In addition, functional status subsumes a health condition (e.g. blindness, amputation, chronic illness) and impairments of different limbs, organs and physiological systems within the body.

These different factors can be measured in different ways: by observation, objective measurement or in a self-report format. Typically, measurement of health conditions and impairments are best done through health examinations and therapy assessments,[1] while activities (basic and complex) can be measured both objectively (e.g. detailed assessment of the nature of

activity limitations), or through self-report surveys (e.g. identifying the presence of activity limitations).

In addition to measures of functional status, one can measure the availability and use of assistive technology and the accessibility of the physical or built environment and transport,[2] and the attitudes and support of others, and the impact of these on functional status. This gives a series of measures "with" and "without" the impact of the external environment, which provides a good way to prioritise interventions. If a person faces many barriers in their environment (e.g. negative attitudes, inaccessible buildings, etc.) the focus of the intervention should be on changing these barriers rather than on intervening to change the individual. The environmental intervention could be implementation (meso-environment) of an existing policy or set of regulations (macro-environment), or development of a policy and set of regulations (macro-environment) to allow for implementation at the meso-environment level.

Over the last two to three decades, many instruments have been developed to assess functional status. These include, for example, the SF-36 (and other SF versions) (Ware & Sherboume, 1992), The Sickness Impact Profile (Bergner et. al., 1981), other measures of activities of daily living, the World Health Organisation's Disability Assessment Schedule (WHO-DAS II) (Garin et. al., 2010), the WHO's International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), and the related core sets developed for use with different clinical conditions (Stucki et. al., 2002), and a range of similar instruments. In addition, there has been a growing number of quality-of-life instruments developed to measure the impact of interventions on people's quality of life (usually including some measures of functional status).

Most of these instruments have been developed with a particular clinical category of people in mind and have limited use as measures for population-based surveys and statistics. While there have been disability statistics collected for many years, these have been problematic due to lack of clarity on what the question is measuring, as well as being highly exclusive measures (i.e. counting in only a few select groups of people). Examples of these include questions that ask if anyone in the household is "deaf, blind, crippled or mentally retarded". Recent developments in the field of disability statistics show that measures asking about difficulties people have in a series of basic activities and allowing the person to respond, not with a mere yes or no, but with a scale of responses (no difficulty, some difficulty, a lot of difficulty or cannot do at all) provide a more transparent and inclusive measure of activity limitations (Schneider, 2009; Schneider et. al., 2009). These questions measure functioning of

the individual and do not take into account (except for use of eye glasses and hearing aids) the impact of environmental factors. Additional questions are required to assess functioning with and without assistive technology and the impact of other environmental factors.

These measures identify people who have difficulties in domains of functioning such as seeing, hearing, mobility, remembering and concentrating, self care and communication, as well as asking about the impact of pain, fatigue, anxiety and depression. These questions have been developed and tested across a wide range of countries, showing good reliability in highlighting similar trends and validity as provided in evidence on how people understand and interpret the questions.

The two main sets of questions are those developed by WHO in the WHO-DAS II (Garin et. al., 2010), and the Washington Group on Disability Statistics Short Set and Extended Set of questions[3] (Washington Group on Disability Statistics, 2010; UNESCAP, 2010; Schneider et. al., 2009). These measures (see appendix for the Short Set) provide a measure of the people at risk for disability and its related disadvantages. Thus, they only provide part of the measurement. Further measurement occurs by using the presence or absence of any functional difficulties in relation to measures of other outcomes, such as educational achievement, employment status, access to services, and social inclusion.

CRITICAL ISSUES

- The key issues requiring monitoring and evaluation must be set out in order to integrate them with the basic measures proposed in this paper.
- What are the platforms available for specific and routine data collection that could be exploited for the purposes of monitoring and evaluating disability mainstreaming and equalisation of opportunities?
- How can DCA advocate for the mainstreaming of disability measures in all data–collection platforms, as is done for gender and other basic demographic variables?
- Use of measures of disability for collecting statistics requires a good understanding of these measures. Therefore, they should not be applied without training.

ENDNOTES

1 Self-reporting on health conditions and impairments is heavily influenced by access to health care and diagnostic services. Hence, self-reporting will show more about the access to these services than an accurate prevalence estimate.

2 These are considered as meso-environment or neighbourhood level factors. The policies and systems that govern them and determine, for example, building regulations would be macro-environmental factors. If the macro-environment does not provide for building regulations, it becomes much less likely to have accessible buildings at the meso-environment level. The individual level measures start from the individual and look at the outcome of the interaction of that individual with the micro- and meso-environment, while the structural level measures start at the macro-environment level and do not focus on the individual.

3 See website for Washington Group on Disability Statistics for more information on the work and products of this group: http://cdc.gov/nchs/washington_group.htm

REFERENCES

Bergner, M., Bobbitt, R.A., Carter, W.B. & Gilson, B.S. (1981) "The Sickness Impact Profile: Development and final revision of a health status measure" in *Medical Care* 19(8):787–805.

Garin, O., Ayuso-Mateos, J.L., Almansa, J., Nieto, M., Chatterji, S., Vilagut, G., Alonso, J., Cieza, A., Svetskova, O., Burger, H., Racca, V., Francescutti, C., Vieta, E., Kostanjsek, N., Raggi, A., Leonardi, M. & Ferrer, M. (2010) "Validation of the 'World Health Organization Disability Assessment Schedule, WHODAS-2' in patients with chronic diseases" in *Health Qual Life Outcomes* 8:51, Epub 2010 May 19.

Schneider, M. (2009) "The difference a word makes: responding to questions on 'disability' and 'difficulty' in South Africa" in *Disability and Rehabilitation* 31(1):42-50.

Schneider, M., Dasappa, P., Khan, N. & Khan, A. (2009) "Measuring disability in censuses: The case of South Africa" in *ALTER, European Journal of Disability Research* 3:245–265.

Schneider, M., Hurst, R., Miller, J. & Üstün, T.B. (2003) "The role of environment in the International Classification of Functioning, Disability and Health (ICF)" in *Disability and Rehabilitation* 25(11–12):588-595.

Stucki, G., Cieza, A., Ewert, T., Kostanjsek, N., Chatterji, S. & Üstün, T.B. (2002) "Application of the International Classification of Functioning, Disability and Health (ICF) in clinical practice" in *Disability and Rehabilitation* 24(5):281-282.

UNESCAP (2010) Final report of the UN Development Account project – Improvement of Disability Measurement and Statistics in Support of Biwako Millennium Framework and Regional Census Programme, prepared by the National Center for Health Statistics of the United States (Head of the Washington Group on Disability Statistics) and the Statistics Division of ESCAP, http://www.unescap.org/stat/disability/analysis, accessed 19 May 2011.

Ware, J.E. & Sherbourne, C.D. (1992) "The MOS 36-item short-form health survey (SF-36) 1: conceptual framework and item selection" in *Med Care* 30:473–83.

Washington Group on Disability Statistics (2010).

World Health Organisation (2001) *International Classification of Functioning, Disability and Health*, Geneva: WHO.

DEAN'S AFTERWORD

This first issue of the Disability Catalyst Africa is published at a time when, in the wake of the first global summit, the world is focused on non-communicable disease. Yet little, if any, attention is being paid to one of the major mani-festations of non-communicable disease on the African continent, namely, disability.

The Catalyst will thus have fulfilled its mission – to place a spotlight on disability; to provide information which can stimulate dialogue; and to provide tools for advo-cacy which can advance disability rights and, in so doing, improve the well-being of people with disabilities.

The Faculty of Health Sciences supports this initiative in the hope that it will strengthen the capacity of academics and students in higher education institutions – as well as policy-makers, managers and practitioners in state and civil society organisations – and, in so doing, mobilise all sectors of society to achieve social change through disability-inclusive development.

Congratulations to all who contributed to the birth of this important contribution to advocacy for disability as a societal priority. We look forward to the Disability Catalyst Africa as an annual publication!

Professor Marian Jacobs

Dean

APPENDIX

Washington Group on Disability Statistics
Short Set of disability measures

Census Questions on Disability Endorsed by the Washington Group

Introductory phrase
The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

	No – no difficulty	Yes – some difficulty	Yes – a lot of difficulty	Cannot do at all
1. Do you have difficulty seeing, even if wearing glasses?				
2. Do you have difficulty hearing, even if using a hearing aid?				
3. Do you have difficulty walking or climbing steps?				
4. Do you have difficulty remembering or concentrating?				
5. Do you have difficulty with self-care such as washing all over or dressing?				
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?				