# Challenges of implementing a disability policy

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## ABSTRACT

This article attempts to address the challenges that still persist in the implementation of disability policies. The international realisation of disability policies is the starting point in the implementation process. Different societies, including those in Africa and South Africa, may hold slightly different views of disability policies, but international disability policies are essential to enable societies to adapt more easily to disability policies. The article investigates the existence of an international disability policy or the lack thereof. There is not yet consensus on a definition of the nature of disability; and the exact number of disabled people in society is still unknown. The challenges of dealing with impairment affect the social, attitudinal, architectural, medical, economic, and political environments. Therefore, in order to address the challenges of disability, one has to be able to define the exact problem of disability. The inaccuracy of figures on people with disability in any society creates challenges in the design and implementation of proper disability policies. The question also arises whether there are any disabilities that are specific to our time, for instance, it is possible that people live longer, and if so, that should have a specific bearing on disability policies and their implementation. The article focuses on the ramifications of disability policies and suggests ways to deal with them.

## INTRODUCTION

Disability policies start with the international realisation that the entire world population is at risk when it comes to the effects of chronic illness and disability

(Zola 1989:401). If a universal disability policy existed, that would make it more convenient for societies to adopt suitable policies to adapt to the challenges that accompany disability. This article focuses on the challenges of implementing disability policies. One such challenge might be the lack of a universal disability policy.

Establishing a perspective on the size and nature of disability as a problem is the first challenge of this article. Disability is not necessarily confined to a small number of members of any population; and disability is also not essentially medical. Impairment can affect the social, attitudinal, architectural, medical, economic, and political environment (Zola 1989:401). A disability policy should therefore address the real problem of disability.

In most industrialised countries where disability policies have been evolving for many years, national policies on disability tend to consist of disjointed combinations of modern inclusive approaches with elements of the rehabilitation, special education and/or custodial care approaches of the past. In developing countries, disability service systems have historically tended to consist of small-scale, rehabilitation, education, training and sheltered employment programmes imported from industrialised countries by churches and NGOs (Metts 2000:23). Interestingly, both industrialised and developing countries have to face the same policy challenges in the form of disjointed and underfunded disability programmes. It therefore seems that disability policies everywhere are restricted by the same resource constraints and appropriateness issues that have long beleaguered their predecessors.

A global challenge for disability policies is to ensure that disabled people have equal access to social and economic opportunities. This commitment is expressed by the United Nations in the World Programme Action (WPA) and the Standard Rules, by the EU in its 1996 Resolution, and by most countries of the world in a variety of ways, including constitutional provisions, legislation and disability policies. These disability policies have two primary purposes:

- to affirm the basic human rights of people with disabilities to equal access to social and economic opportunities; and
- to create environments in which people with disabilities can maximise their capacity for making social and economic contributions (Metts 2000:35).

## THE RESEARCH PROBLEM OF DISABILITY

Independent of the unit of study, be it a city, a state or a community, it is estimated that one out of eight people has a disability. The numbers of people with a disability therefore create the impression of a statistical minority. One may also get the impression that if the general health of the population is

improving, the disability statistics will also decline. Studies conducted by Zola (1989:402) of chronic illness and disability, however, provide a different and less positive picture.

Even if the number of children is not increasing, the proportion of those with disabilities will. Over the last few decades, the United States has experienced a doubling in disability statistics (Zola 1989:403). The cause of these disabilities is not the focus of this article, but these causes have obvious policy ramifications and two main causes are therefore briefly mentioned here. Learning disabilities are one of the groups of disabilities that are growing most rapidly in schools and on campuses (Faigel 1985, in Zola 1989:403). The ageing world population places higher demands on service providers, so that assisting the older members of the population therefore also becomes part of the challenge of a disability policy. Against this background, the question arises whether disability policies can be successfully implemented.

## The nature of disability

We live in an age in which technological advances allow many young people to survive with what was previously called terminal diseases (Zola 1989:404). A similar trend is observable in the young adult group. People go beyond middle age and tend to live longer. The question then arises whether disability policies consider the nature of these changes. Another aspect of disability is that the condition is often static –people often survive for decades beyond the onset of their original disease or disability (Zola 1989:406). It is evident that disabilities are diverse, but, in terms of policy options, they intersect with the spheres of housing, transport and work.

## Housing and the built environment

The housing needs of people with disabilities involve more than the need for access to the place where the person lives. The built environment includes the design of the inside of dwellings (the heights, widths, depths of doorways, sinks, tables, cupboards, as well as the entrances and exits to and from a person's external world (Zola 1989:407). The question in a given community is whether housing for people with disabilities is limited exclusively to care institutions (such as retirement communities or villages for people living with disabilities). In the total population of a country it is not strange to find that one out of ten people has special architectural requirements for his or her home. In the age group from 60 to 75 years, one out of three people will need a ramp and one-half railings.

The disability needs cost for houses are relatively low if the necessary facilities are incorporated in the original design. However, the cost of renovating

a house for disability facilities can be substantial. The adaptation of their housing environment gives people with disability a sense of safety and security. If people with disability are catered for in their own homes, there is also a lower demand for care institutions. The nature of the built environment may indeed have a direct etiological effect upon the cause of disability, whereas correct and appropriate disability facilities could prevent or postpone certain disabilities (Zola 1989:410).

According to Metts (2000:30), six principles define universal design:

- flexibility in use;
- simple and intuitive use;
- perceptible information;
- tolerance of error;
- low physical effort; and
- size and space for approach to use.

These principles should serve as guide for disability policy-makers to address accessibility issues in a holistic, integrated, cost-effective and positive way.

## Transportation

For transportation systems to work well, consumers generally require speed, endurance and access if people are going to use such systems to move from one place to another, rather than walk. A wheelchair is, for instance, another way of moving from one location to another. However, large segments of the disabled population avoid wheelchair use because of the stigma that is perceived to be attached to it (Zola 1989:411). It is therefore not strange to find older people rejecting the use of a wheelchair because they falsely believe that using one defines them as frail invalids. Golf carts or other kinds of motorised carts and scooters and special adapted bicycles could also help people to move from one place to another. An adapted privately operated automobile is often a preferred mode of transportation (Zola 1989:412). The electronic age has also brought new add-ons for such vehicles, such as automatic gears, cruise control, power steering and brakes, electronic windows and seats, glare control and voice signals. However, these kinds of adapted automobile are exclusive to some industrialised parts of the world

The adaption of mass transportation remains costly and problematic. Ensuring the accessibility of means of transport such as cars, buses, trains or planes involves considerable expenditure. Generally, mass transportation is largely inaccessible to people with disabilities. Different countries place a different emphasis on time and the speed of transportation (Zola 1989:414). The nature of a country's transport policy and its level of adaptation for people with

disability requires a public policy commitment. The implementation of such a policy is not always clear in terms of numbers.

## Work and the work environment

Most employment policies for people with disabilities attempt to keep up with the universal principles embodied in the World Programme Action and Standard Rules for hiring quotas, reserved employment schemes and rehabilitation strategies to address the issue of unequal access to employment and unequal opportunities in the workplace. The private sector also tends to become involved in partnerships with employers, employees and organisations of disabled people (Metts 2000:25).

Paid work will remain a major source which sustains people; a shortening of the work day and the work week is a possibility in future. This implies that more people will spend more time outside the work force or workplace than in it. At the same time, productive unpaid roles in the home, the family, and voluntary associations are likely to assume more importance (Zola 1989:416). In countries with shrinking populations, more work will be available for previously excluded or underemployed groups, including minorities, women and people with disabilities. Flexibility in work time and a decrease in work hours will make it easier for people with disabilities to fit into the work schedule. A more computerised and decentralised work force will make it easier for people to work from home. This would also suit people with disabilities. A key element of a disability policy is therefore to prevent persons with disabilities from leaving the work force and to sustain their participation as long as possible. In this regard, it is interesting that a vast majority of employees with a disability do not acknowledge this fact at work. Whether they do so out of fear of discrimination or stigma, they simply do not self-disclose (Zola 1989:419). In public policy, disability should be emphasised in the wider context of the entire work force.

## Global perspectives on disability

The international recognition of disability has increased over the last couple of decades. This represents a marked shift from a medical model to a more empowering social model of disability. In simple terms, the medical model regards a person with an impairment as having a medical defect and as therefore being in need of medical care to eliminate or treat the medical condition (Gathiram 2008:146). The social model of disability does not necessarily perceive disability from the perspective of a given impairment and does not focus on impairment as a function of anatomic loss or a degree of functional limitation. The social model focuses on the characteristics of a disabling society

(discrimination and prejudice) which make it difficult for persons with a physical disability to meet their needs (Gathiram 2008:147). The social model advocates respect for people with disabilities. The interaction between the physical, social and policy environments and people with disabilities is therefore emphasised in the social model. However, the social model has also been criticised by activists because it fails to recognise medical needs fully, and fails to take into account the integration of people with disabilities in all spheres of life and its implications.

It is clear that, on a global scale, disability is multidimensional. In any attempt to understand disability, a framework should be created that identifies the factors that create disability. In this regard, the World Health Organisation has developed the International Classification of Functioning, Disability and Health (ICF) (Gathiram 2008:147). This International Classification focuses on both interpersonal factors and the external environmental factors relating to disability. It is clear that the International Classification attempts to create a holistic understanding of disability using a bio-psychosocial approach. It is also critical to recognise the relationship between poverty and disability and the need to integrate economic and social development. A disability policy should address at least two critical issues, namely income security and the complete integration of disabled people into social and economic life.

## DISABILITY POLICIES AND STRUCTURES IN SOUTH AFRICA

Like many other countries, South Africa has also a lack of reliable information on the nature and prevalence of disability. It is estimated that 16 per cent of South Africans are disabled. These figures have brought social planners to recognise the high economic cost of excluding disabled people from the economy. Before 1994, under apartheid rule, the state contributed to the neglect of black people with impairments. Over 80 per cent of disabled children in South Africa live in extreme poverty. Many disabled people live in the lowest income households and they also have the lowest levels of education in the population (Gathiram 2008:147).

Today, South African disability policies are rooted in a rights-based approach. This implies a minimum standard of living, equitable access and equal opportunity to access services and benefits (Gathiram 2008:147). The national social welfare policy operates in a mixed economy, with partnerships between Government, civil society and the private sector. In 1997, this approach led to the formation of an Integrated National Disability Strategy (INDS), which was based on the United Nations Standard Rules for the Equalisation of Opportunities for people with disabilities (Gathiram 2008:147). The Integrated National Disability

Strategy in South Africa has led to the creation of institutional structures for the delivery of services to disabled people and their families in the President's Office (Gathiram 2008:47). After the last elections a separate Ministry was created to address these issues, the Ministry of Women, children and persons with disabilities.

Apartheid rule left South Africa with a legacy of poverty and underdevelopment; and this has a bearing on the services available to people with disabilities in this country. Today, free means-tested healthcare is provided to disabled people at public hospitals and clinics (Gathiram 2008:147). The Department of Health has adopted community-based rehabilitation (CBR), which is seen worldwide as a solution to the social integration of disabled people in society (Gathiram 2008:148). Therefore there is clearly a strong emphasis on the social model of disability.

The chief provider of social security in South Africa is the Department of Social Development, via a disability grant system and social services to disadvantaged people. Since 2005, the administration of social security has been moved to a separate agency, the South African Social Security Agency (SASSA). Some challenges that have arisen in the implementation of the existing disability policies include a lack of coordination and communication between programmes, departments, Government and civil society (Gathiram 2008:148). To ensure successful implementation of disability policies, improved coordination within institutional structures is clearly needed, as well as the roll-out of the promised integrated service delivery system.

## Implementation challenges in the South African system

Despite a constant preoccupation with policies, commissions, committees and position statements, none of these ever reach full implementation (Gathiram 2008:151). The challenge is therefore to review policies to ensure successful implementation. Although the social disability model has been accepted, people's eligibility to access a disability grant is still based on a medical model of assessment. Thus, the *Social Assistance Act* (Act 59 of 1992) defines a disabled person eligible for a grant as a person

> "… who has attained the prescribed age and is, owing to his or her physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him [or her] to provide for his or her maintenance".

This definition clearly excludes the social model of disability and also incorporates the belief that disabled people are incapable of work. This means

test can therefore create an incentive not to work (Gathiram 2008:152). The estimated unemployment figure of 40 per cent (Gathiram 2008:152) of the total population has a bearing on the employment of disabled people. The question remains what the concept of disability is. The next section attempts to explain some considerations that are changing the contemporary concept of disability.

## The changing concept of disability

The functional limitations aspect of disability refers to an inability to perform the roles and tasks expected from a person within a social environment. The functional component of disability relates to a person's individual health status and enables (or makes impossible) the distribution of people with disability in the general population. The component also seems to be the basis for the definition of disability in South Africa's Disability Act (Act 52 of 1992). Schalock (2004:205) provides a list of functional movements that are instrumental for daily activities (see Table 1).

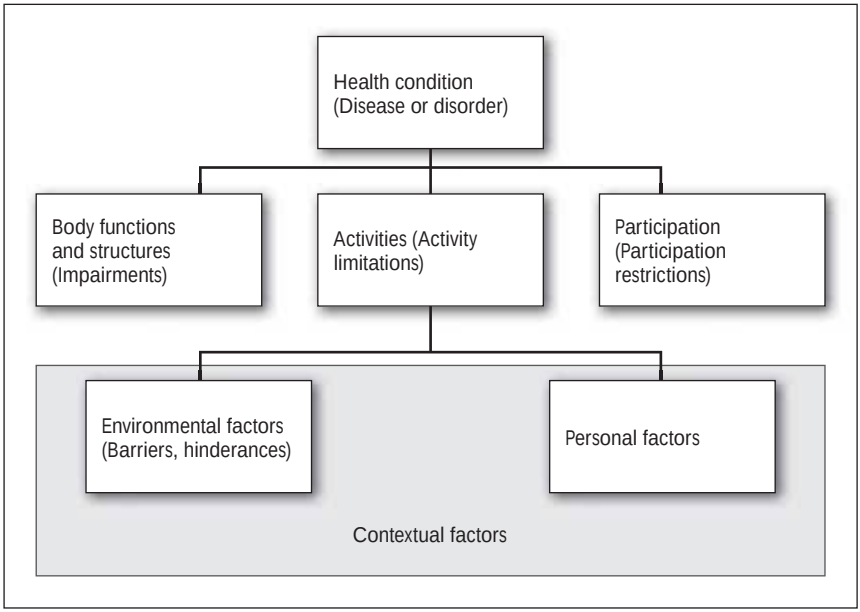
**Table 1: Functional indicators commonly used in measures of functionality**

| Activities of daily living | Instrumental activities of daily living | Physical tasks |
|---|---|---|
| Bathe | Heavy housework | Walk |
| Dress | Shop | Bend |
| Transfer | Light housework | Stand |
| Toilet | Meals | Steps |
| Eat | Money | Lift |
| | Phone | Reach |
| | | Grasp |
| | | Hold |

**Source:** Schalock 2004:205

The World Bank Health Organisation (2001) also emphasises functional limitations that are influenced by social and environmental factors. Figure 1 depicts the World Health Organisation's view of disability.

**Figure 1: The international classification of functioning in health**




**Source:** Schalock 2004:206

Another aspect of the disability paradigm is personal well-being, which is reflected in what Schalop (2004:205) calls positive psychology and quality of life. Positive psychology comprises positive experiences, positive personality, and positive communities and institutions. The quality of life component is well known to people with disabilities. Eight core indicators of quality of life are listed in Table 2.

A third aspect of disability is the increasing individualised support by way of resources, strategies, education and interests that promote personal well-being (Schalock 2004:207).

A fourth aspect that contributes to the changing disability paradigm is personal competence and adaptation. Schalock (2004:209) relates different kinds of intelligence (such as practical and cognitive intelligence) to adaptive behaviour. The aspects that influence the changing paradigm are summarised in Figure 2.

## The implications of the new disability concept for policy

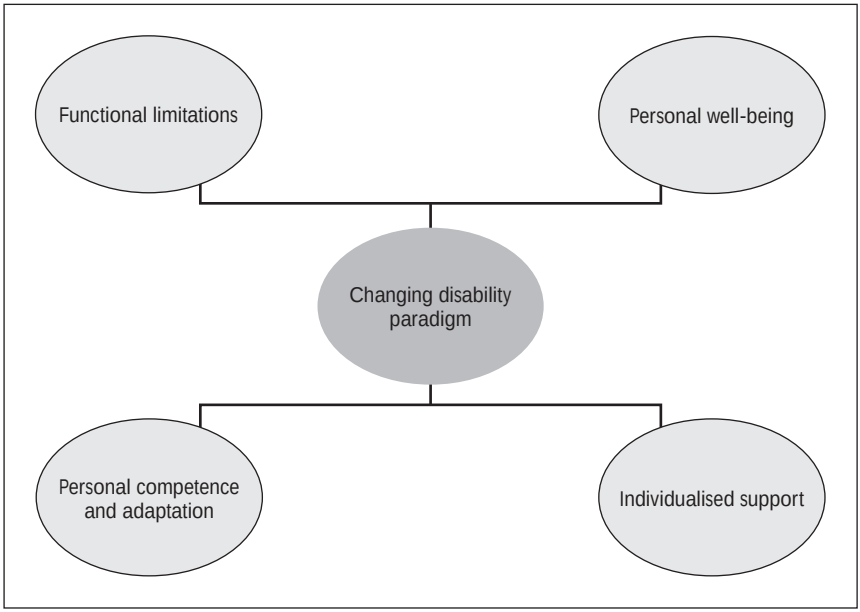
The core concept of disability for the purposes of policy is that disability is a natural part of human experience and in no way diminishes a person's right to

**Table 2: Core quality of life domains and indicators**

| Domain | Indicators |
|---|---|
| Emotional well-being | Contentment (satisfaction, moods, enjoyment) |
| | Self-concept |
| | Lack of stress |
| Interpersonal relations | Interactions (social networks, social contacts) |
| | Relationships (family, friends, peers) |
| | Support (emotional, physical, financial, feedback) |
| Material well-being | Financial status (income, benefits) |
| | Employment |
| | Housing |
| Personal development | Education |
| | Personal competence |
| | Performance |
| Physical well-being | Health |
| | Activities of daily living |
| | Leisure |
| Self-determination | Autonomy/personal control |
| | Goals and personal values |
| | Choices (opportunities, options, preferences) |
| Social inclusion | Community integration and participation |
| | Community roles |
| | Social support |
| Rights | Human |
| | Legal |

**Source:** Schalock 2004:207

**Figure 2: The changing disability paradigm**




**Source:** Schalock 2004:205

participate fully in all aspects of life. Policies should therefore focus on all aspects of disability. The functional aspects of disability need to be incorporated into policies. Disabilities are diverse – at the one end of the continuum, one finds a person living with an impairment who is not disabled by his or her environment; at the other end of the continuum, one finds people whose environment brings about disablement (Schalock 2004:242).

Personal well-being and satisfaction of the identified predictors (see Table 2) should be funded and covered by disability programmes. The challenges faced by disability policies include finding ways to evaluate the support needs of people with disabilities and then designing appropriate service delivery (Schalock 2004:212). Perhaps one of the biggest challenges to disability policy is to address competencies and skills. It is simplistic to claim that a person is either disabled or not disabled. The difficulty for disability policy lies in the aspect of eligibility for a grant (Schalock 2004:213). The changing concept of disability requires constant changes in policy and policy implementation. The future of the disability paradigm will depend on the members of society and the way they interact with people with disabilities. It could be reiterated that disability is not simply a condition characterised by functional limitations, but is also the product of interaction between individual people and their surroundings.

## IMPLEMENTATION EXPERIENCES WITH DISABILITY POLICIES

Employment is perhaps the most critical factor for people with disabilities. Disability policies can assist disabled people by protecting them from discrimination. Ambiguity in disability policies may, however, have an effect on evaluations to determine whether discrimination has taken place. The best hope for the implementation of disability policies lies with those who are responsible for compliance. Policy-makers can at best guide policy proposals to present operating principles – employers who are not properly informed about disability can create a significant obstacle to eliminating discrimination in employment for people with disabilities (Percy 2001:635).

It has to be admitted that the nature of a specific disability, such as mental disability, could create problems with employment for a person living with this disability. In the case of psychological illness, people who do not share this handicap have difficulty in understanding the realities of such a condition. In the past, often heavy medication and institutionalisation was the primary treatment for mental conditions, but this approach is changing.

The implementation of disability policies and legislation by the private sector is normally slower than that in the public sector. In the private sector, different types of businesses proliferate, which makes control over the implementation of disability policies difficult. Nevertheless, although disability policies do not ensure full compliance, some strides are being made, even if it is difficult to measure the scope of the compliance and subsequent change (Percy 2001:639).

A few major obstacles could be identified in people's experiences of the implementation of disability policies. In any instance where compliance with a disability policy requires substantial expenditure, one will find a slower rate of implementation. The exact definition of disability, plus the way it is described in the disability policy, might also create challenges with implementation. It is always more difficult for disability policies to protect persons with mental disabilities than for them to protect physically handicapped persons. A lack of sufficient knowledge, resources or energy makes effective enforcement of disability policy mechanisms difficult. More research definitely needs to be done in understanding what does and does not work in implementation (Percy 2001:639).

### The effect of policy ambiguity on implementation

The success of a disability policy can, amongst other things, be based on how the policy facilitates relationships among partners, including those with

disabilities. Disability job seekers need to navigate their way through disability policies. Often one finds that only the most skilful of jobseekers are able to navigate the service systems. Closer cooperation between disability institutions and agencies could therefore be a remedy for policies that are complex in some way.

An understanding of the conceptual underpinnings of a policy can influence its smooth implementation. Policy ambiguity can lead to misunderstanding of a policy and could eventually result in policy failure (Cohen, Timmons and Fesko 2005:223). The understanding of a policy is critical from two perspectives; the one is that of the designers and administrators, and the other is that of the frontline workers and the intended beneficiaries of the policy. Policy conflict and ambiguity are often the result of different views of the same policy. A difference in views can arise, either because of different goals or because of activities and projects that attempt to achieve the goals. If policy ambiguity becomes public, it can trigger uncertainty around the issue in question. The greater the ambiguity in a policy, the more likely it is that institutions charged with disability policies will experience problems in the implementation of the policy (Cohen *et al.* 2005:223).

Policy ambiguity can both create and minimise conflict. In the policy design phase, policy ambiguity is often convenient to see a policy through its adoption. During implementation phase, however, policy ambiguity creates uncertainty among the different role players. Conversely, clear language can promote a sense of responsibility among all stakeholders.

## THE CHALLENGES FOR THE BENEFICIARIES OF DISABILITY POLICIES

The intended recipients of disability policies often experience vast challenges because of the nature of their disability. Challenges range from attitudinal problems to a lack of information. The disability community is often relatively powerless (Prince 2004:59). On the one hand, disability is personal experience, but at the same time, it is a public issue of great significance. Although legislation and policies can define disability, in practice, matters come down to persons that experience difficulties with their daily living activities, or that have a mental or physical condition or a health problem that reduces the kind or amount of activities the persons can do. Adult disabled people commonly have lower levels of education, far higher rates of unemployment, lower earnings and lower household incomes (Prince 2004:61).

Getting people with disabilities on the agendas of government in the form of plans and policies is relatively easy. The challenge lies in getting serious

attention from policy-makers and officials to put disability policies into action. Societal standards and perceptions about what is 'normal' are often promoted through advertising, the mass media and general discourse. This leads people with disabilities to experience segregation, a disqualification of their citizenship rights, and denial of full acceptance (Prince 2004:71). The representation of children and youth with disabilities is generally far less powerful than that of business and industry groups. In fact, the representation in the media of almost any other social policy group, relating, for instance, to health care or education, is more powerful than that of disabled groups (Prince 2004:72).

## CONCLUSION

Anyone who has attempted to define disability has to confront the diversity of impairments associated with the concept, the wide range of physical and social settings in which those impairments may or may not be relevant, and the variety of cultural meanings that are used to make sense of the interaction between a person who has an impairment and his or her environment. Universal policies do provide some definitions of disability and so do various countries that have their own definitions of disability policies. The challenge with the implementation of these policies remains not only a universal challenge, but also a challenge for every country. As was stated at the beginning of this article, universal disability policies provided by the world's large international organisations still require global commitment to equalising opportunities for disabled people. These international entities are best positioned to facilitate the necessary integration and coordination of disability policies. One can conclude that the challenge of this leadership is not yet being met and that in some instances, such leadership is weak and ineffective.

No matter how detailed a disability policy is, the practice seems to be plagued with a number of common challenges. Therefore, irrespective of which country policy is being implemented in, those people whose mobility, communication, medical needs, or cognition differ from social norms find themselves confronting institutions that are not well suited to harnessing and enhancing their abilities and potential. Interestingly, large-scale public sector institutions whose underlying values stress efficiency and whose operating technologies emphasise standardisation may be less likely to incorporate the variety introduced by disability. One would want to see more disability policies that stress participation. This means that society should be able to fully incorporate a person living with a disabling condition.

The implementation of disability policies faces the challenge of creating compatibility between individual variation and societal institutions. This might

lead to secondary effects that ripple through family and community systems. Disability and disability policies present society, policy-makers and officials with complex challenges and opportunities to look beyond efficiency as the main measure of individual and institutional worthiness. The whole concept of quality of life should therefore be broadened in the twenty-first century. The challenge of implementing disability policies is not becoming any easier with the rapidly changing economic conditions, including global competition, deregulation, and the growth of the service sector. Most policy-makers attempting to transform existing disability policies are still in need of education and training to obtain an accurate understanding of disability. Despite all the global and national efforts to address the disability needs successfully, the core deficiencies of disability policies remain.

The failure to meet the needs of disabled people can be summarised in terms of a few factors. Firstly, there is still the political factor of a lack of long-term strategic plans and policies for disability. Secondly, there is the social factor of the existence of discrimination against people with disabilities who face additional constraints due to particular cultural beliefs and practices. Thirdly, in some countries, there is a geographical factor in the form of a lack of services and programmes in remote areas, which might have a higher rate of disabled persons. Fourthly, there is still a lack of quantitative data on the numbers of disabled people, as well as qualitative information on their situation. It is difficult to develop a proper disability policy and consequent successful implementation with a lack of such data and information. Finally, one finds a lack of technical and financial resources needed to implement disability policies successfully. All these factors will have to be addressed to improve the lives of people with disabilities.

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