

Executive summary

Introduction

Important progress has been made in recent years to expand policy, programs and support to address the needs of persons with disabilities in Guyana through the further development of sector specific projects focusing largely on rehabilitation and education. But important and pressing challenges still remain to be addressed. Persons with disabilities are often the most disadvantaged of all groups in society. Many do not have access to education and employment which leads to social and economic exclusion. Persons with disabilities are often trapped in a cycle of poverty and disability; each being a cause and consequence of one another.

Further work is required to deal with the challenges and realities facing those living with a disability in Guyana. Equal opportunities for persons with disabilities have to be created through investments in education, health, social care, employment, and recreational sectors to allow persons with disabilities to lead full and productive lives. Similarly a holistic approach, addressing the perceptions of disability as well as related policies, is required to ensure successful integration of persons with disabilities.

Approaches to tackling the restrictions imposed upon persons with disabilities must be multi-disciplinary and multi-dimensional. A **dual approach** to disability is required: activities should be designed to address the particular needs of persons with disabilities through sector specific projects; and, the needs of persons with disabilities should be considered within the planning framework of any program to ensure the needs of persons with disabilities are met within any programmes target population.

This report is the outcome of a survey designed to create a detailed profile of persons with disabilities in Guyana. This has enabled a recommended action plan to be developed, identifying future priorities that can be used to target assistance (policy, programs and services) for persons living with disabilities in Guyana.

The survey

The survey involved detailed interviews with a sample of 1,485 persons with disabilities in regions 4, 6, 7 and 9. This is approximately 2 – 3% of the disabled population in Guyana. There has been an overwhelming positive response from persons with disabilities participating in the survey (response rate of 99%). This is the first time that many of them have been approached to tell their story about the issues they face on a daily basis with regard to accessing services, and participating within their community and wider society. Persons with disabilities must participate in the definition of their needs, the design of projects to address those needs, and be included in the management of systems to deliver them. NCD believes that the participation of persons with disabilities at all levels of planning and implementation of this survey is testimony to an effective recommended policy action plan that defines and addresses the needs of persons with disabilities.

The survey included a full range of disabilities including visual (30%), hearing (21%), mobility (58%), self-care (34%), communication (54%) and remembering (linked to recall and learning disabilities) (57%). The International Classification of Health, Functioning and Disability (ICF) measured disability, examining the interaction between the impairment, environmental and attitudinal factors, accounting for personal factors, environmental factors and levels of participation.

Key themes and issues

Education

Access to education can be limited, or entirely prevented, for persons with disabilities. The survey data identifies transportation, financial constraints, attitudes (individuals, peers, parents and teachers), teaching and care provisions, curriculum and physical access as interacting factors that create barriers to education. Fifteen per cent (15%) of all respondents had never attended school; and the proportion dramatically increases to 42 % when looking at those aged less than 16 years.

Most respondents (61%) currently in education attend mainstream education facilities and one-third (29%) attend special educational needs (SEN) schools. Guyana's current education facilities face challenges providing a continuation of education facilities for persons with disabilities, particularly at post primary level. Only 16% of respondents aged between 11 and 18 years are in any form of secondary education (including vocational). The results highlight the need for renewed efforts to expand SEN provisions, both within mainstream and specialist education and training providers, in all regions in Guyana.

Health

Access to healthcare services including basic health care, specialised health care or rehabilitation treatment can be difficult for persons with disabilities to access. The survey found that access to healthcare provisions differs by type of impairment; respondents with physical (72%) and visual (55%) impairments more frequently accessed services in comparison to those with hearing/speech (44%) and learning disabilities (27%). Utilisation of existing health services is not only dependent upon individual factors (type of impairment, location, transportation and financial) but also on the capacity of initial contact in health services to recognise/diagnose impairment and refer the person to the most appropriate service. Although the survey data is limited it suggests that health sector faces challenges in providing accessible treatment and rehabilitation in hinterland regions (60 – 80% of respondents in these regions have not accessed any treatment or therapy). The survey shows that generally there is a low level of utilisation of assistive aids (10 – 48% of respondents use an assistive aid) and many are struggling to access basic medical supplies to meet their needs.

Between 20 - 50% of respondents are born with a disability. The data indicates that prenatal care and education, screening programs for all children and early intervention programs could reduce the occurrence and impact of disability.

Employment

Only 17% of respondents (of those above 18 years) are currently in employment. Employment of respondents differs by sector: self-employment (46%) and private sector (29%) are the most frequently reported. High clusters of respondents are employed in semi-skilled or unskilled roles, for example, domestic and labouring. The disparity in employment roles may be attributed to socio-economic variants and attitudinal barriers that prevent equality of opportunities in the workplace and access to educational and training qualifications.

Many unemployed respondents (40%) have lost their job as a result of gaining their disability. Almost half (47%) of unemployed respondents are willing to work but they require training, assistance or both. The evidence demonstrates a lack of focused rehabilitation services for persons willing and able to return to work. Nine per cent (9%) are qualified, skilled and able to work; they only require the opportunity.

Social & recreational

The opportunity for social participation by persons with disabilities in Guyana is indirectly restricted through limited access to education and employment. The stigma surrounding disability unfortunately often deters participation in social and recreational activities. Almost half of respondents experience difficulties participating in recreational activities (43%) and community activities (56%). Social participation often occurs within a limited context of family (62%) or close friends (32%). Fourteen per cent (14%) of respondents are totally socially excluded; they are neither attendees nor invitees to social occasions and are rarely visited in their own homes.

Family

Disability does not just affect the individual but impacts on the entire family. Most respondents (90%) live with their immediate or extended family. The survey shows that the impact of caring for a family member is threefold: caring responsibility tends to fall largely with one member of the family (63%); financial difficulties (79% of respondents families have experienced financial difficulties); and emotional.

Often caring limits the main carers level of engagement in employment, 50% of respondent carers are not employed, of which 11% had to give up work to care. Reduced family income then creates difficulties meeting additional costs of disability including medical treatment and medicines, transportation, specialist equipment and dietary products. This impact of caring can perpetuate the vicious cycle of poverty and disability.

Focus group discussions explored the emotional impact of caring for a person with a disability. Main care givers report stress, anxiety and additional financial concerns. An extended support network, often of family members and close friends, is vital to assist the main care giver; those without are likely to be particularly prone to stress and anxiety. Families need support and assistance to identify and access treatment, education, information and support for their family member with a disability.

Access

Access in the context of disability refers to barriers that prevent persons from disabilities participating in society. Accessibility must be considered in three contexts: physical, attitudinal and information. Access is a cross cutting theme which spans across all services and support and is addressed specifically under education, health, employment, social and recreational participation and family.

Despite two-thirds (65%) of respondents believing that their disability limits their ability to conduct their daily activities, their ability to access services is likely to have a greater impact on their level of participation rather than their medical impairment. Often architecture, construction, maintenance, design, service, systems and policies create access restrictions to buildings, private and public spaces and services (health, education, social, economic, political, transportation, civil and legal, and utility).

Almost half of respondents (44%) have experienced negative attitudes or behaviours as a result of their disability. Negative attitudes have a dual impact on persons with disabilities: an internalisation of negative views can create feelings of low self-esteem and achievement hindering participation; and reduced participation pushes them further out of public view. The experience of focus group participants demonstrates that even simple interaction with persons with disabilities helps to reduce discrimination and prejudice. The evidence suggests that empowerment of persons with disabilities to participate in society is key to change public perceptions.

Equal access to information is key to ensure full participation in society for persons with disabilities. It is not simply about alternative formats but also about raising awareness of where and how to access further information, services, support and advice.

Based on the results of the survey a number of policy recommendations have been made. Details, investments, agencies and priorities are addressed in the sector recommendations of the full report.

Summary Recommendations: an Agenda for Action

Area	Recommendations
Education	Improve screening programs in the first years of nursery and primary school to detect disabilities and introduce early intervention programmes to raise awareness of child's future needs
	Expand and develop existing special educational needs training, resources, referral systems and equipment for all teachers
	Further explore feasible models to integrate SEN facilities into mainstream education provisions
	Expand methods of community based support for families to ensure their child with a disability accesses an education
Health	Expand existing health services in all regions to ensure persons with disabilities can access basic and specialised medical care through increased rehabilitation training, screening programs, record keeping
	Improve awareness of existing services and benefits of utilisation for persons with disabilities
	Training all healthcare providers dealing with persons with disabilities to improve communication with persons with disabilities and their families
Employment	Implement nationwide public awareness campaign for equal employment opportunities for persons with disabilities under existing legal obligations through introducing disability awareness business briefings and training provider work attachment programs
	Expand and develop mainstream and special educational needs training provisions for persons with disabilities
Social & recreational participation	Develop guidelines to increase awareness of persons with disabilities as a user of facilities and their specific needs
	Improve the awareness of disability with community based organisations to enable them to include of persons with disabilities in their activities and programs
Family	Review innovative methods of providing financial support to families
	Raise awareness of the rights and services available for persons with disabilities with all organisations providing family services