

TABLE OF CONTENTS

Acknowledgements	i
List of Table.....	ii
List of Abbreviations	iii
1 Terms of reference and structure of the research process	1
1.1 Terms of reference.....	1
1.2 The structure and process of research	1
2 Introduction and methodology	2
2.1 Background and context of the study	2
2.2 The questionnaires used for data collection.....	6
2.2.1 The screening questionnaire	6
2.2.2 Detailed questionnaire.....	6
2.3 Statistical analysis of data and presentation of results	7
2.3.1 Level of statistical significance	7
2.3.2 Populations for each variable: 'N'.....	8
2.3.3 Average percentages	8
2.4 Factors considered in the analysis	8
3 Results	9
3.1 Summary of lifestories and focus groups.....	9
3.1.1 Themes across life stories	9
3.1.2 Themes across focus groups	12
3.2 Summary on disability prevalence and distribution	14
3.2.1 Prevalence of disability	14
3.2.2 Distribution of disabled people across the provinces.....	18
3.2.3 Causes of disability	18
3.2.4 Age of onset of disability	19
3.3 Summary on the use of proxy reporters	19
3.4 Summary on severity of disability.....	20
3.5 Summary on services needed and received by disabled people	20
3.6 Summary on Assistive devices	21
3.7 Summary on Education	22
3.7.1 Summary and conclusions on school attendance	22
3.7.2 Summary of school attendance by age of onset	24
3.7.3 Summary of school attendance by type of disability	24
3.7.4 Summary of school attendance by number of disabilities.....	25
3.7.5 Summary of school attendance by race.....	26
3.7.6 Summary of highest education level reached	27
3.7.7 General conclusions on education.....	27
3.8 Summary on employment	28
3.9 Summary on transport	29
3.10 Summary on accessibility of the environment.....	29
3.11 Summary on social security	30

3.12	Summary on participation within family life.....	31
3.12.1	Summary of level of integration within the family	31
3.12.2	Summary of 'feel' words used by respondents.....	31
3.12.3	Summary of how society should treat disabled people.....	32
3.12.4	Summary of what the President should do to improve the lives of disabled people	32
3.12.5	General summary and conclusions for the chapter on participation within family life	33
4	Conclusions	34
4.1	Examples of information that can be used for planning immediately.....	34
4.2	Examples of information that require further research to complement the survey data. ..	35
4.3	Answers to questions posed in the introduction	36
Appendix A	38
	Probe Questions for screening questionnaire	38
1.	Seeing	38
2.	Hearing	38
3.	Communication problems (speaking, being understood & conversing with people)	38
4.	Movement activities	39
5.	Getting around or moving around.....	39
6.	Daily life activities.....	39
7.	Intellectual disability	39
8.	Learning difficulties	40
9.	Emotional disorders (psychological and psychiatric).....	40

ACKNOWLEDGEMENTS

Sincere thanks and gratitude goes to the following people who have contributed in many ways to the realisation of this study and report:

- Steve Motlatla, Nobayeti Dube, Sam Motimela and Thuli Khanye for their tireless efforts during the fieldwork period of this study;
- Mrs Christelle Kotzenberg and Mr Maluta Tshivhase of the Directorate: Chronic Diseases, Disabilities and Geriatrics, Department of Health who were always willing to listen to the woes of the project, provide encouragement and who provided a most amicable and pleasant working relationship throughout the project;
- Members of the reference team who contributed their thoughts, ideas and criticisms throughout the process; (The reference group comprised representatives from the following: Disabled People South Africa, Disabled Children's Action Group, South African Federal Council on Disability, Disability Action Research Team, Statistics South Africa, Medical Research Council, Office on the Status of Disabled People, Wits/Tintswalo Community Based Rehabilitation Training Programme, the Department of Health and the C A S E research team).
- David Everatt, who, as director of C A S E, provided ongoing support and encouragement;
- The large number of enthusiastic and hard-working fieldworkers who collected the data;
- The many comments and questions posed in the course of feedback workshops in the provinces;
- Lastly, but not least, the respondents who provided their time, information on their lives and views on disability.

LIST OF TABLE

Table 1: Prevalence rate, by Province.....	14
Table 2: Prevalence rates, by province and race.	15
Table 3: Disability prevalence, by age and race.....	16
Table 4: Prevalence rates, by type of disability.	17
Table 5: Distribution of total sample of disabled people across Provinces.....	18
Table 6: Causes of disability (N=2223).....	18

LIST OF ABBREVIATIONS

AD: Assistive device

CBO: Community based organisation

ECD: Early childhood development

ICIDH: International Classification of Impairment, Disability and Handicap

NCSNET/NCESS: National Commission on Special Needs in Education and Training/ National Committee on Education Support Services

OBE: Outcomes based education

WHO: World Health Organisation

"We also count"

The extent of moderate to severe reported disabilities and the nature of the disability experience in South Africa

Summary report

This report is a summary of the full report on the national baseline disability survey. The summary report briefly discusses the background and methodology, highlights some of the more important findings and incorporates the concluding chapter of the main report. The purpose of this report is to provide a framework of the full survey to allow the reader to then 'dip into' the full report more easily. The sections of the summary report mirror the chapters in the full report. A separate executive summary for the survey of assistive devices and the service provider interviews are presented with each of those individual reports.

1 TERMS OF REFERENCE AND STRUCTURE OF THE RESEARCH PROCESS

1.1 Terms of reference

In December 1996 the Department of Health issued a tender to undertake a disability survey project in order to provide information on the following terms of reference.

- a) A review of the literature available on the subject to create a body of working definitions of different disabilities and terminology.
- b) An analysis of all disabilities ranked according to prevalence.
- c) An analysis of the causes of disability across different age groups and geographical locations.
- d) An analysis of the source and amount of funding of services for people with disabilities.
- e) A quantitative and qualitative analysis of the resources available including their distribution and their accessibility.
- f) An analysis of felt service needs of people with disabilities.
- g) An analysis of the needs of service providers.
- h) An indication of the need for assistive devices for independent living and the accessibility thereof.

1.2 The structure and process of research

The Community Agency for Social Enquiry (C A S E) submitted a proposal and was awarded the tender in July 1997. The tender proposal presented by C A S E responded to these terms of reference within a research structure that included the following:

- A literature review which reviewed issues of definitions, terminology, methodologies and existing national and international prevalence data;

- A series of eight focus groups¹ and five life stories with disabled people to provide qualitative information regarding the nature and cause of disability, the problems faced by disabled people and their felt needs, as well as providing some understanding of the availability and appropriateness of services;
- A pilot and full national survey of 10 000 households nationally covering all provinces, four race groups (African, Coloured, Indian and White) as well as rural, urban and metropolitan areas to provide an analysis of all disabilities in terms of sex, province, age, causes, felt needs and other key demographic variables. This information was used to determine the prevalence of disabilities as well as describe the disability experience as reported by disabled people or their proxy reporters;
- A series of interviews with service providers to obtain information on the amount and type of funding available for disability-related services and available resources and their location, as well indications of needs of service providers;
- An analysis of the availability of assistive devices and difficulties in providing assistive devices services at provincial level.

2 INTRODUCTION AND METHODOLOGY

2.1 Background and context of the study

Disability is a complex issue with many factors affecting and impacting on a person's experience of their disability. In this study we measured the extent of moderate to severe reported disability and described the nature of the disability experience in South Africa at the end of the Twentieth Century. When considering the experience of disability we focussed on issues such as severity, services needed and received, assistive devices, education, employment, transport and environmental accessibility, social security, participation within the family, how a person feels about being disabled, how disabled people would like society to treat them and what the President should do to improve the lives of disabled people.

Disability is not a static entity that can be measured in a straightforward and objective manner using a simple standardised test or instrument. It is a subjective entity whose presence is determined, to a large extent, by the person experiencing it.

For purposes of this study disability was defined as a limitation in one or more activities of daily living. The activities used were those of seeing, hearing, communication, moving, getting around, daily life activities, learning, intellectual and emotional. For each activity a series of probe questions were used to assist the person being interviewed in identifying possible activity limitations or disabilities experienced by themselves and/or members of their household. The

¹ Although eight focus groups were planned, nine were in fact run as an opportunity arose to run an additional one with disabled women attending university.

probe questions are presented in the Appendix and are important as they provide the definition of each type of disability. If a person answered yes to one or more of the questions, they were counted as being disabled. The type of disability was determined by the category of the question, which was answered in the affirmative. When answering the questions, the respondent was asked to compare themselves or someone else in their household to another person of the same age and background who does not have any difficulties. A few examples are presented here.

- If a person said that they or someone in their household had difficulty in seeing ordinary print at arms length even when wearing glasses or contact lenses or if they are blind in one or both eyes they were counted as having a seeing disability. The same person could also have one or more of the other eight disabilities.
- If a person said that they or someone in their household had difficulty going up or down two flights of stairs or in using public transport, they were counted as having a moving around disability. The same person could also have one or more of the other eight disabilities.
- If a person said that they or someone in their household had difficulty controlling their temper when they are with others or controlling their anxiety, they were counted as having an emotional disability.

The probe questions were used to identify the disabled people but were not coded for analysis. The outcome is that the data do not differentiate within the disability or activity limitation categories. A blind person will be coded as a person with a seeing disability just as someone who is partially sighted. Similarly, a Deaf person would have been counted as having a hearing disability as would have been a person with partial hearing. Someone in a wheelchair would be counted as having a movement activity and moving around disability as would someone who has a missing lower limb. Hence, the data does not tell us about the experience of being Deaf or blind or severely physically impaired. It only tells us about the experience of having a seeing, hearing and movement activity limitation.

We all experience limitations of some sort to a greater or lesser extent at some point in our lives. However, few of us experience the level of discrimination meted out to people who, for example, use wheelchairs, have intellectual disabilities, learning problems, are blind or deaf, are unable to communicate or are just not able to look after themselves. Society has created barriers (physical and attitudinal in nature) that have been most effective in marginalising these people with disabilities.

The focus of the survey was on the 'traditional' categories of impairments. But only people, who reported themselves or members of their household to have noticeable (to themselves and/or to others) limitations in the activities listed above, were counted. For example, someone with albinism would only be identified as disabled if the person reported having seeing problems, someone with epilepsy was only identified as disabled if they reported having problems in daily life activities, or learning, and so on. What the study does not report on is the recurring scenario where someone with albinism cannot find employment because of people's prejudice vis a vis someone who has skin colour different to what he or she should have. A survey focussing on

handicaps or participation restrictions would have identified the person with Albinism as being handicapped or having a participation restriction.

The results are a count of the number of people with reported disabilities or activity limitations. The results are not a count of the number of people in South Africa who have an impairment (problems with body structure and function) or handicap (restrictions in ability to participate in society) as defined in the World Health Organisation's Classification of Impairments, Disabilities and Handicaps: ICIDH-2 (Beta-1 and Beta-2 versions).² The results suggest that the prevalence rate for disability measured on this survey focuses on people with moderate to severe disabilities which are permanent in nature. By permanent we mean that the disability has lasted or is expected to last for more than twelve months. The survey did not count people with chronic illnesses (e.g. asthma, epilepsy, diabetes, etc.) unless the respondent said that a person experienced the activity limitations or disabilities asked about in the probe questions.

We visited households and interviewed one person about the whole household. We did not visit any full time residential care facilities or boarding facilities at special schools but did ask that members of the household, living in these facilities who were financially dependent on the household, be included.

We visited 9260 households covering in correct proportions the nine provinces, rural, urban and metropolitan areas, four race groups and all age groups.³ This is the first time we have a national picture of the extent of disabilities and the nature of the disability experience in South Africa.

We obtained information on 42 974 people of whom 2 435 were identified as being disabled (i.e. having one or more activity limitations). If we extrapolate this figure to the general population, it means that there are between 2.3 million and 2.5 million people with disabilities in South Africa (5.7% - 6.1% of the total population).

What is more interesting than merely counting the number of people with disabilities, is to look at the nature of the disability and the experience of people with disabilities. The statistics tell us what factors are important in determining the nature of the experience while the qualitative data from the focus groups and life stories give a more in-depth description of what it is like to be disabled.

The results presented in this report must be clearly understood within the context of what the survey project set out to do. It set out to provide national and provincial prevalence rates for

² ICIDH-2: International Classification of Impairments, Activities and Participation. A Manual of Dimensions of Disablement and Functioning. Beta-1 draft for field trials. World Health Organisation, Geneva, 1997 and Beta-2 version for field trials released in 1999.

³ The sample included an oversampling for Indian households as well as for the Northern Cape. This was done to ensure that the final number of respondents in each of these categories was sufficient to provide reliable statistics. The data was weighted down before being analysed.

disabilities as reported by the respondents and their proxy reporters as well as a quantitative analysis of the respondents' personal experience of their disability. The focus groups and life stories complement this picture by providing in-depth qualitative information about personal experiences of disability as reported by the focus groups participants and the life story tellers.

Of importance at this stage of reading this report,⁴ is to understand the differences between the perceptions of activists and leaders within the disability movement and those portrayed in the results of the survey. The activist perceptions of disability are developed through their own experiences as well as contact with numerous disabled people and their families. The nature of these perceptions are clearly reflected in the life stories and focus group discussions and do represent an important component of what makes up the disability experience in South Africa today. The survey data captures some of these experiences when analysed according to factors such as age of onset, number of disabilities and the race of the disabled person. Any policy maker would be foolish to ignore the work that has been undertaken by the disability sector.

What these experiences do not do is contextualise the number of people affected within the total number of people in South Africa. Also they do not always take into account the many people who have an identifiable disability or activity limitation but who do not, for whatever reason, see themselves as part of the disability movement. Some of the reasons for this include a lack of awareness of the discrimination they face as disabled people, not wanting to identify themselves as 'disabled', or just that they in fact do participate to their satisfaction and hence do not take part in the disability movement.

The survey, on the other hand does identify all people with an activity limitation, whether they see themselves as disabled or not and whether they participate within the disability movement or not. In that sense it contextualises the people with disabilities within the total South African population. It includes the elderly person who has had two hip replacements and who struggles to walk without a walking stick; the middle-aged housewife who struggles with her hearing due to a progressive disease affecting hearing; the young boy with chronic middle ear infections who develops a learning problem because the infection is not properly treated, and so on. These are all people who were identified in this survey as being disabled through the asking of the probe questions. The survey does to some extent 'dilute' the generally negative experiences of disability activists but provides another perspective on disability.

The challenge to all of us is to find a way to marry these two perspectives or realities in a way that maximises their benefits in policy development and service provision.

⁴ This and the following few paragraphs explain why the survey and its results have been an area of strong contestation and debate between members of the reference group and the authors. This led to the Office on the Status of Disabled People stating that they are not able to endorse the survey.

The results provide many useful indications for planning both for the Department of Health and other government departments as well as for the disability sector. Some results, however, do require further research before the data can be used meaningfully for planning purposes. The full report provides further details on these different uses of the data.

2.2 The questionnaires used for data collection

2.2.1 The screening questionnaire

The screening questionnaire provided information on all members of the households and was used to calculate the prevalence rate as well as identify respondents for the detailed questionnaire.

The screening questionnaire was administered to the senior women of the household or another person who could provide detailed information about the whole household. This person (respondent 1) was asked a series of questions about each member of the household. The questions included:

- Demographic questions on province, type of area, type of dwelling;
- Household matrix: Name of each member, age, sex, relationship to respondent 1, employment status and whether disabled or not (after asking the probe questions);
- If a person was identified as being disabled, on completion of the probe questions, a series of questions were asked about that person. These included:
 - Type of disability;
 - Age of onset (as understood by the respondent);
 - Cause (as understood by the respondent);
 - Whether it was temporary or permanent;
 - Confirmation of the disability;
 - Household income.

2.2.2 Detailed questionnaire

The detailed questionnaire was administered to 1703 disabled people identified on the screening questionnaire. The detailed questionnaire provided data on the nature of the disability experience. The questionnaire was divided into a number of sections as listed below: These sections correspond generally to the chapters of the report.

- Type and cause of disability;
- Severity;
- Services needed and received;
- Assistive devices;
- Education (only if disabled before the age of 18 years);
- Employment (only if 15 years or older at the time of interview);
- Transport and environmental accessibility;
- Social security;

- Level of integration within the family and general life experience;
- Proxy reporters (only asked of proxy reporters).

The type of questions asked varied from straightforward factual questions (e.g. what is the highest level of education you have passed?) through to questions asking about the perceptions of the respondents on needs of disabled people, (e.g. the educational needs of disabled people), and opinions on various topics, and so on.

2.3 Statistical analysis of data and presentation of results

The main statistical analyses undertaken were frequency counts, cross tabulations and loglinear analyses. The significance level used as a cut off point between significant and non-significant results was p-value of ≤ 0.05 or 5%. The p-value is not quoted unless of particular interest (e.g. when highly significant or just borderline significant). It can be assumed that if a result is said to be significant that the p-value is ≤ 0.05 .

2.3.1 Level of statistical significance

Statistical significance in this context means that the results have picked up a real difference between two groups on a specific variable being measured. The difference measured is due to the different effects of the two groups and not just because of chance. For example, the employment rate for men and women is significantly different. This means that the variable of sex (the two groups being men and women) has a real effect on whether a disabled person is employed or not. This does not automatically imply that being a disabled woman causes one not to be employed. It just describes the relationship between the two variables without specifying the causal relationship. In some instances we have tried to provide some possible explanations why certain results were obtained. Most of these explanations require further verification before being accepted. In addition, there are often two or more possible explanations for one result. One example is the fact that there are significantly more African disabled people in urban areas than there are African disabled people in rural areas. One explanation could be that urbanisation causes more disabilities (e.g. through motor vehicle or industrial accidents). Another explanation is that disabled people come to the urban areas to find services. One or both of these explanations could be causing the results obtained. The results themselves do not indicate which is applicable or whether both are applicable.

We have generally only reported on the significant results except where the fact that the result is not significant is of particular interest. Sometimes a table includes a range of variables (e.g. type of disability) all cross-tabulated with the same variable (e.g. highest level of education passed) to see the relationship, in this case, of type of disability on the level of education reached. Not all variables (type of disability) are necessarily significantly correlated with the one variable (education level reached) but will still be reported in the table. The significant results will be highlighted with an asterisk.

2.3.2 Populations for each variable: 'N'

Not all respondents were required to answer all sections and not all respondents answered the sections they were meant to answer. This means that although the total sample of disabled people is 1703, we did not always have 1703 responses to analyse for each question. The population (or N) varies for each question. The text makes it clear exactly what the N is for each analysis. Sometimes the N is given for a table if it is felt that it would facilitate the reading of the table.

All figures are given as percentages and, generally, rounded off to the nearest percentage unless the actual count of number of respondents is given. Use of percentages facilitates comparison between groups when the count in each group is different. Sometimes the number (or count) of respondents included in a category is too small to make meaningful statistical conclusions. This will be highlighted in the text. This occurs frequently, for example, when analysing by race where the numbers for Coloured and Indian respondents are often too few to allow for accurate statistical analyses.

In some questions the respondents could give more than one answer, as for the type of disability. This means that the total numbers for these questions will be in excess of 1703 or 100%.

2.3.3 Average percentages

In some tables there is an average percentage given in the last row. This average percentage reflects the proportion of respondents out of the total sample of disabled people giving the response indicated in the relevant column. For each row, the result is significant if the difference between the result in that row is significantly larger or smaller than the average. If the row percentage is larger than the average it means the response occurs more frequently than the average for the population. If the row percentage is smaller than the average one, it means the response occurs less frequently than the average for the population.

2.4 Factors considered in the analysis

The main factors we considered and used in the data analysis were the following:

- Age of onset;
- Type of disability;
- Number of disabilities;
- Sex;
- Race;
- Geographical location;
- Whether direct or proxy reporter.

These factors were used in almost every question analysed. There were some other additional factors considered in some of the analyses, such as provinces.

However, these variables are reported on only when the results are statistically significant.

3 RESULTS

This section first presents summaries of the lifestories and focus groups, followed by the sections as listed here:

- Prevalence and distribution of reported disabilities;
- Proxy reporting;
- Severity of disability;
- Services needed and received by disabled people;
- Assistive devices;
- Education;
- Employment;
- Transport;
- Environmental accessibility;
- Social security;
- Participation of disabled people in family life;
- Concluding remarks.

3.1 Summary of lifestories and focus groups

3.1.1 Themes across life stories

Five lifestories were collected from disabled people. The storytellers included a Deaf African adult man, a young White woman with a severe learning disability who is a honours student at university, an African woman with aphasia who was a journalist before her stroke, a young white man with cerebral palsy who is a computer specialist, and an African man with Albinism who is a lawyer.

3.1.1.1 Attitudinal barriers

A theme that cuts across most of the life stories, irrespective of disability is the intolerance of the society in which we live towards people with disabilities which leaves them with a feeling of marginalisation and a sense that they have been sidelined from the broader society. What comes through strongly in the stories is the disabling effect of intolerance and prejudice which impacts profoundly on the lives of the narrators.

Joseph's story in particular highlights society's lack of tolerance towards people with albinism and the result of segregating learners with albinism in special schools together with blind and visually impaired learners as a result of their visual impairment. As is evident in Joseph's story, the visual impairment can be accommodated in mainstream schools and the benefits of social integration were in his opinion critical to him developing the confidence and the social skills to feel on a par with his peers. Joseph compares himself to other people that he knows with

albinism, who attended special schools and, as a result, are withdrawn and lacking in confidence. Joseph himself has been unable to find employment since obtaining his post graduate law degree, as well as a further legal qualification. He attributes this to the prejudice of prospective employers.

Thuli who has aphasia also feels marginalised as a result of her disability and her lack of success in getting a disability grant. She feels that she lives in a society that does not care for people with disabilities, especially those that are disadvantaged.

Thobile's story also highlights the lack of support from the broader hearing society towards Deaf people which comes through in a Soweto 1976 incident when hearing people did not intervene when Deaf people were arrested or beaten by police. The lack of intolerance of society towards Deaf black people extended to the hearing society as well as the national Deaf organisation and the current larger disability movement. The reason for the marginalisation of Deaf people is their lack of ability to communicate effectively with the hearing world as most hearing people do not know Sign Language and there is a lack of trained interpreters, specifically for the black Deaf community.

Nancy feels that her mother saw her almost entirely in terms of her learning disability. It was probably very difficult for her mother not to focus on the learning disability at the expense of seeing her child as a person who happened to have a learning disability. The medical model puts a great deal of emphasis on diagnosing pathology and the special educational model, at that time, was also geared to pathologising and excluding students with special needs from the mainstream. Consequently it is not surprising that Nancy has internalised the idea that she is pathological to the extent that it is very difficult for her to see her learning disability as not being central to her identity.

Andrew's story highlights his efforts, as a person with cerebral palsy, to take responsibility for the fact that most people do not engage him in conversation due to their difficulty in understanding him. He feels that it is his responsibility to communicate intelligibly with others who do not take the time to adapt to his largely unintelligible speech. He wants to learn to control his voice so as to make himself more intelligible. However this is extremely difficult, if not impossible, for him to do.

3.1.1.2 Barriers to employment

All the narrators except for Nancy (learning disability), who has never looked for a job as she is still studying, emphasized the difficulties involved in finding employment. Ironically, Joseph (albinism) who is the most qualified, is having the most difficulty finding a job. Andrew (cerebral palsy) recounted that when he was interviewed, employers were obviously not interested in interviewing him after seeing the extent of his disability. In terms of the Deaf community, Thobile stressed that black Deaf people do not have the skills to find jobs due to the inadequacy of their education which did not provide them with the academic training necessary

to study further but focussed on vocational training (gardening, painting, welding and woodwork). Due to high unemployment in the rural areas, many Deaf people come to Gauteng to look for work. The organisation's office provides them with some basic support, a floor to sleep on and a letter indicating that they are looking for work. The situation for Thuli (aphasia) is different in that she feels that she is unemployable due to the severity of her communication limitation and her inability to read and write anymore.

3.1.1.3 Barriers to education

Interestingly, irrespective of whether the narrators were mainstreamed or attended special schools, most of the stories reflect problems in the educational system. Joseph (albinism) was mainstreamed successfully and speaks about the impact of segregating other learners with albinism in special schools. He says this segregation prevents them from becoming socially integrated into the broader society they have to live in after they have finished school. Nancy (learning disability) and Andrew (cerebral palsy) experienced both special schools and mainstream schools. It seems that they preferred the mainstream experience although Andrew complained about the social barriers that existed out of the school context. He never socialised with the other students out of school, indicating that putting learners in a mainstream school will not necessarily ensure their social integration. Nancy emphasized that she never could focus on her social life and have much leisure time, due to the number of hours she needed to devote to studying.

3.1.1.4 Refusing to be silenced

All narrators irrespective of their disability had all their lives, fought and are fighting the system that tries to silence or marginalise them. Some have taken on this task as individuals. Thuli writes poems which she sends out to embassies, members of parliament and former comrades. Others are taking leadership roles in community based organisations (CBOs). Thobile continues to fight for the rights of the black Deaf community his organisation serves despite the lack of response from the hearing world and the disability movement. Joseph has chosen to get involved in working for the society for albinism. Nancy and Andrew fight their own battles on a daily basis as individuals to ensure that their needs are met.

3.1.1.5 Racism

Both Thuli (aphasia) and Thobile (Deaf) see themselves as doubly disadvantaged in terms of disability and race. Thobile notes the discrepancies that still exist between black and white Deaf people. White Deaf people in Johannesburg have access to a few white internationally trained or skilled Sign Language interpreters whereas there are no black trained or skilled interpreters in Soweto. Thuli sees racism as responsible for causing her disability in the first place. During apartheid she had to go into exile where in turn she was further damaged by assassination attempts and the stress of constant international travel resulting in a stroke and consequent aphasia. Apartheid resulted also in the lack of available resources for people with disabilities.

3.1.1.6 Needs

There was consensus across Thuli (aphasia), Joseph (albinism) and Thobile (Deaf) that disability grants were essential for people with disabilities who were unemployed. More importantly, people with disabilities needed to have equitable access to jobs. Joseph advocated that the definition of affirmative action be broadened to include people with disabilities and that government needed to prioritise affirmative action so that the problem of unemployment could be redressed. Thuli advocated that assistive technology and housing assistance needed to be made available for people with disabilities who were impoverished. She wanted a culture of volunteerism to be developed so that able bodied people could volunteer to spend time with people with disabilities and assist them in meeting their needs.

Nancy (learning disability) and Joseph (albinism) felt that it was important for learners with disabilities to be mainstreamed with able bodied learners and any special needs accommodated so that social integration could occur from an early age. It was important to them that learners not be ghettoised into special schools which should not become dumping grounds. On the other hand Thobile focussed on the importance to him of learning and using Sign Language at Deaf schools which provide the first opportunity to Deaf children to become enculturated into the Deaf community. However, they too are not dumping grounds and need to be equitable in terms of the level of education offered to Deaf students.

3.1.2 Themes across focus groups

Nine focus groups were run. The participants ranged from disabled adult men and women, parents and caregivers of both young disabled children and of adults with intellectual disabilities, adolescents, university students and people with epilepsy. The groups were kept homogeneous according to age and sex or disability type.

3.1.2.1 Attitudinal barriers

All of the participants spoke of suffering from discrimination and other people's ignorance and insensitivity. Parents of disabled children were often rejected by their former friends because of their child's disability, and received little support. Participants spoke of people's ignorance and lack of knowledge, which leads them to fear and ostracise disabled people, or to behave in an insensitive way. There is clearly a need for awareness-raising campaigns.

3.1.2.2 Barriers to employment

Work was a major concern for participants. The immediate concern of parents of disabled children is that they themselves often cannot work because they need to care for their child, due to inadequate child-care facilities. Their other concern centres around their anxiety about the future – they would like to know that their child will one day be able to get a job and sustain a measure of independence. They also worry about what will happen when they are no longer able to care for their children, because at this stage in South Africa, there are very few jobs or job

opportunities available for people with disabilities. The direct reporters explained how being able to earn an income has allowed them to be more independent and has improved their self esteem. People with disabilities still suffer from discrimination in the workplace, and struggle to find jobs.

3.1.2.3 Needs

a) Accessible information

Many of the participants mentioned the fact that they often struggle to obtain information about services that are available, support groups, or even information about their disability. Information dissemination needs to be more co-ordinated and thorough, and people need to be able to access information about schools, treatment, and so on, more easily.

b) Services

The lack of infrastructure, services, and transport contribute to making life difficult. In rural areas and in cities, poor quality roads or crowded pavements make movement difficult. Public transport is not geared for disabled people, and participants expressed frustration about not being able to lead a normal life, get to school or work and so on, due to these factors. Service provision was generally seen to be the responsibility of government and other groups working in partnership. Physical accessibility issues were seen to be a priority by many participants.

3.1.2.4 Integration into society

Participants suggested that integration into society will be more possible if efforts are made to educate children about issues around disability, in order to keep them from becoming prejudiced and discriminatory as many adults today are. Another way of ensuring integration into society of people with disabilities is to encourage the use of terminology that is inclusive and affirming, and to avoid hurtful or degrading language.

3.1.2.5 Education

While participants had mixed views on education, there was generally support for mainstream schooling because it is not so isolating, and contributes to the full participation of individuals in society.

3.2 Summary on disability prevalence and distribution

This section presents the summary of data collected on the screening questionnaire. These are the data on prevalence and the distribution of disabled people across the nine provinces. The prevalence rates give the proportion of the total population (e.g. for one province, one race group, rural versus urban dwellers or the whole country) who are disabled. The distribution of disabled people show how the total sample of disabled people are distributed throughout the nine provinces.

The percentages given in the tables relate to the total population being referred to. For example, in Table 1 the Western Cape has a prevalence rate of 3.8% and the Northern Cape has a prevalence rate of 5.4%. However, the Western Cape has a much higher total population than the Northern Cape. The total number of disabled people in the Western Cape will, therefore, be higher than for the Northern Cape, and more resources will be required in the Western Cape than the Northern Cape. The same issue applies to the prevalence rates given for different race groups and geographical locations. Before the percentages can be used for planning, they must be translated into actual numbers by applying the percentage to the relevant population figure as given out by the Statistics South Africa or other sources of population statistics. These actual numbers will then provide indications of the extent of provision required.

3.2.1 Prevalence of disability

- The North-West province (3.1%), Western Cape (3.8%) and Mpumalanga (4.5%) have disability prevalence rates which are significantly lower than the national average, while the Eastern Cape (8.9%) and Kwa-Zulu Natal (6.7%) have significantly higher disability prevalence rates.

<i>Province</i>	<i>Prevalence rate (%)</i>	<i>Total 'N'⁵</i>
Western Cape	3.8	4081
Eastern Cape	8.9	6743
Northern Cape	4.5	888
Free State	5.8	2814
KZN	6.7	8900
North West	3.1	3596
Gauteng	5.2	7753
Mpumalanga	4.5	2963
Northern Province	6.3	5198
Total (Average %)	5.9	42936

Table 1: Prevalence rate, by Province.

⁵ The total 'N' in this case refers to the number of people on whom information was collected through the screening questionnaire for each province. The percentage in the middle column indicates the proportion of the 'N' that were identified as disabled.

- In the Northern Province, Eastern Cape and North West Province, the Whites had a higher prevalence rate than the other races. No other race differences were found.

<i>Province</i>	<i>African (%)</i>	<i>Coloured (%)</i>	<i>Indian (%)</i>	<i>White (%)</i>
Western Cape	3.9	3.9	2.3	3.3
Eastern Cape	9.0	6.1	-	11.8
Northern cape	4.0	4.3	-	7.4
Free State	6.1	0.0	-	5.6
KZN	6.9	9.4	5.3	6.2
North West	2.9	-	-	5.8
Gauteng	5.5	5.5	1.8	4.5
Mpumalanga	4.7	-	-	2.6
Northern Province	5.8	-	-	10.4
Total (average %)	6.1	4.5	4.8	5.3

Table 2: Prevalence rates, by province and race.

- Africans (6.1%) have a significantly higher prevalence rate than other races. African respondents who live in urban areas are more likely to be disabled than their rural counterparts.
- The disability rate varies significantly across age groups. There is a steady increase in the prevalence rate between the ages of 0 and 10 (from 1.6% to 3.3%) and between the ages of 35 and 60 (from 5.1% to 14%). The disability rate rises sharply after the age of 70 (13% for the category 71-75 to 24% for the 80+ category). There is a slight, but significant, fall in the disability rate between the ages of 61 and 70.

<i>Age categories</i>	<i>African (%)</i>	<i>Coloured (%)</i>	<i>Indian (%)</i>	<i>White (%)</i>	Total (%)
1-5	1.7	0.6	1.3	1.5	1.6
6-10	3.3	1.7	1.0	5.6	3.2
11-15	4.7	2.6	1.9	5.2	4.5
16-20	4.6	2.1	1.0	2.4	4.1
21-25	5.1	3.4	3.0	1.4	4.6
26-30	5.3	5.4	3.5	4.1	5.1
31-35	5.2	5.1	3.4	5.1	5.1
36-40	6.6	3.7	5.2	5.0	6.0
41-45	8.2	4.8	5.9	6.8	7.5
46-50	10.1	9.0	5.5	7.7	9.3
51-55	12.6	12.7	13.4	9.0	11.9
56-60	15.3	14.8	9.3	8.2	13.7
61-65	16.6	12.3	17.1	7.8	14.3
66-70	14.3	4.4	-	9.3	12.2
71-75	13.9	18.2	-	9.6	13.4
76-80	23.8	-	-	13.3	20.9
81+	27.5	-	-	18.6	24.1

Table 3: Disability prevalence, by age and race.

- White children between the ages of 6 and 10 are more likely to be disabled than children from other races.⁶ The higher prevalence for White children could be explained by the better access to services. The White children are, therefore, surviving medical conditions or traumas more often than children of other races but remain disabled. African respondents between the ages of 16 and 25, and above the age of 56 are more likely to be disabled than similarly aged respondents from other races.
- The majority (58%) of disabled respondents had more than one disability and almost a third of our respondents had more than three disabilities. Rural respondents between the ages of 0 and 10 (59%) were more than twice as likely to have three or more disabilities than their urban counterparts (24%). This suggests that people in rural areas do not have access to services which could prevent a relatively minor disability or impairment develop in to a major one.

<i>Type of disability</i>	<i>Prevalence rate (%)</i>
Movement activity	2.0
Daily life activities	1.8
Seeing	1.7
Moving around	1.7
Learning	1.2
Emotional	1.1
Intellectual	1.1
Hearing	1.0
Communication	0.8

Table 4: Prevalence rates, by type of disability.

- African respondents (1.9%) were more likely to have a sight disability.
- White males were most likely to have a hearing disability.
- Males are, in general, more likely to be diagnosed as having a communication disability than females.
- Coloured males are more likely have a movement activity disability than coloured females. There are no other significant group or sex differences in the distribution of movement activity disabilities.
- There were no significant differences in moving around disabilities by race or sex.
- Coloured women were less likely to experience limitations in their daily life activities than coloured males. There were no other significant differences by race or sex for this type of disability.
- African males were significantly more likely to be classified as having an intellectual disability than other males or African females.
- African and White male respondents were more likely to be classified as having a learning disability than Coloured or Indian males. African males were also more likely to have a learning disability than African females. There were no significant differences, by race, among female respondents.
- African males were more likely to be classified as having an emotional or psychiatric disability than African females. There were no other significant differences by race or sex for this type of disability.

⁶ However, if the total number of disabled children between the ages of 6 and 10 years are considered there would still be many more African than White children in that age group as the total African population is much higher than the White population.

3.2.2 Distribution of disabled people across the provinces

- The highest proportion of disabled people live in the Eastern Cape, KwaZulu-Natal and Gauteng. The smallest proportion of disabled people live in the Northern Cape. The distribution of the different types of disabilities does not differ much across the nine disability types.

<i>Province</i>	<i>Proportion of total sample of disabled people (%)</i>
Eastern Cape	23.7
KwaZulu-Natal	23.5
Gauteng	15.9
Northern Province	12.9
Free State	6.5
Western Cape	6.2
Mpumalanga	5.3
North West	4.4
Northern Cape	1.6

Table 5: Distribution of total sample of disabled people across Provinces

3.2.3 Causes of disability

<i>Cause of disability</i>	<i>%</i>
Illness	26
Don't know	21
Before and during birth	19
Accident	15
Other	9
Violence	5
Witchcraft	3
Ageing process	2
Total	100

Table 6: Causes of disability (N=2223).

- Respondents were asked to give their understanding of what the cause of the disability was. The results presented below are not confirmed diagnoses by medically trained personnel or therapists.
- Respondents in our survey gave illness as the most common cause of disability. Surprisingly, about one in every five respondents did not know the cause of their disability. Almost one-fifth of respondents said that their disability was caused by an event prior to, or during, birth. The other most frequently mentioned causes of disability were accidents (15%), violence (5%) and witchcraft (3%). The high number of people who did not know the cause of their

disability could be linked to the lack of services to diagnose the impairment and/or the lack of information provided to people by medical personnel. This is particularly the case in rural and African areas.

- The most common illnesses given as causes of disability were high blood pressure (14% of all illnesses); unspecified illness (8%); epilepsy (8%); ear infection (7%); psychiatric illness (7%); hereditary illness (7%); diabetes (6%); arthritis (6%); and polio (4%). All percentages given in this point are relative to the total number of people who gave illness as a cause of their disability.
- Indian males are most likely to mention the ageing process.
- The only respondents to suggest witchcraft as the cause of their disability are African.
- Coloured respondents are more likely than African respondents to mention accidents as the cause of their disability.
- African respondents were more than twice as likely than other respondents to be unaware of the cause of their disability.
- African and white male respondents were more likely to mention accidents or violence as the cause of their disability than their female counterparts.
- Female African respondents were more likely to mention illness and ageing as the reasons for their disability than African males.
- An illness was most likely to cause the disability when the respondent was older than 30 (55% of respondents fell into this category).
- Accidents or violence were most likely to be noted as causes of disability between the ages of 19 and 50 (55% for accidents and 80% for violence).
- The reason for the disability was more likely not to be known if the disability started when the respondent was younger than 18 (50% of all respondents in this category).

3.2.4 Age of onset of disability

- African males are more likely to be disabled between the ages of 19 and 30 (16% of males and 13% of females) while African females are more likely to become disabled after the age of 30.
- Rural African respondents were more likely to be disabled at birth (20% of rural Africans) than their urban counterparts (16%). This could be linked to the lack of adequate pre- and peri-natal services for Africans in rural areas. Urban African respondents were more likely to become disabled between the ages of 19 and 30 (16%) than rural Africans (12%).

3.3 Summary on the use of proxy reporters

The situation regarding proxy reporters in this study is that just under half of the respondents were proxy reporters (47%). Of this group, nearly half (45%) are the mothers of people with disabilities. Proxy reporters made up the majority of the respondents for those people with intellectual, communication and learning difficulties. The majority of people under the age of thirty were not directly interviewed. Regarding the employment situation of proxy reporters, just

over half wanted to work while only 22% actually had a job. Only 2% were paid for taking care of the person with the disability which matches with the data that shows that 76% of proxy reporters were a close family member. The issue of care taking obviously puts financial strain on the caregiver. Almost half of those who had jobs left the person with the disability at home with someone or at home alone.

3.4 Summary on severity of disability

The respondents were asked to rate the severity of their disability as being no problem, mild, moderate or severe. They rated the severity without any assistance, with an assistive device, with assistance from another person and with both an assistive device and assistance from another person.

The provision of assistive devices and personal assistance have a highly significant impact on how respondents rated their disability or activity limitation. The number of respondents who said their disability was severe was 58% with no assistance. When an assistive device was used the number rating their disability as severe dropped to 5%. However, it is not clear whether the high number of people who say assistive devices are not applicable to their disability just have not been exposed to the possibilities as yet. When assistance from another person was provided the severe category reduced from 58% of respondents to 12%. When both an assistive device and personal assistance were provided the severe category was reduced from 58% of respondents to 4%.

The respondents who rated their disability as severe most often were those with moving around and daily life activities and movement activity disabilities. Respondents with learning, hearing and emotional disabilities rated their disability as severe the least often. The provision of either assistive devices or personal assistance or provision of both together had the greatest impact on people with movement activity, moving around and daily life activities disabilities. The respondents with these latter disabilities were also least likely to say that assistive devices were not applicable to their disability.

The number of disabilities a person has influences the degree of severity when no assistance is provided. However, when an assistive device and/or personal assistance is provided the severity is greatly reduced for all people no matter how many disabilities they have.

These results provide clear justifications for providing both assistive devices as well as personal assistant services.

3.5 Summary on services needed and received by disabled people

Respondents were asked whether they had needed any services in the past or presently, and whether they had received any services whether they needed them or not. Health services are the

most received and needed service, and welfare and educational services are the least received services.

Health, medical rehabilitation and assistive devices services were the services reported as needed most often. Of those respondents who said they needed a service, the best served were those requiring health and traditional healer services where three-quarters and two thirds respectively, received these services. Only two out of every five persons needing medical rehabilitation and assistive device services actually received the service. Less than a fifth of people needing educational, counselling, welfare and vocational training services actually received these services.

Whites and Indians were the most likely race groups to receive medical rehabilitation services, Indians the most likely to receive assistive devices services, and Whites to receive educational services. These differences highlight the unequal provision of services across the race groups. Females are more likely to receive assistive devices services than males but the reasons for this are not clear.

The majority of respondents depend on the state for services rendered. Whites are more likely to make use of private services as opposed to Africans, Coloured and Indian respondents, who are more likely to make use of government services.

People with a moving around, moving activity and daily life activities disabilities are more likely than people with other disabilities to have received welfare services and assistive devices services. These results are consistent with later results indicating that these people are also more likely to have disability grants and/or to use assistive devices.

Services being too expensive and people not having money (to pay for services or transport) are seen by respondents as the biggest problems experienced with services.

3.6 Summary on Assistive devices

Assistive devices (AD) are a crucial component of service provision for disabled people. The rate of severity of disability decreased significantly through the use of assistive devices and there is an increasing need for assistive devices with increasing age.

Indian and White disabled people are more likely to be using assistive devices than Africans and Coloureds with disabilities. The majority of AD users live in formal metropolitan and urban areas. These results reflect the fact that access to services through finance and awareness are strongly linked to the ability to obtain and maintain assistive devices.

Children attending special schools (primary and secondary levels) are more likely to access and use assistive devices than those attending mainstream schools. However, it should be

remembered that only very few disabled children attend special schools and that those who do also tend to be more advantaged, and hence, are more likely to also be AD users.

It appears that the chances of employment are higher for disabled people who are using assistive devices. However, this finding cannot be interpreted in isolation of many other variables such as access to resources, education, age of onset of the disability as well as the number of disabilities. Further research is required to determine the relative effects of these variables on employment. The question remains as to whether being an AD user makes it easier to find employment; whether having employment makes it easier to afford an assistive device or whether both AD use and employment are determined by other variables.

Assistive devices are mostly used by people with moving around, moving activity, seeing, daily activities and hearing disabilities. The use of assistive devices by people with communication or emotional disabilities is limited. The most commonly used assistive devices are for personal mobility, information/communication and personal care.

The majority of assistive devices for information and communication are obtained from private sources. Those for personal mobility, personal care and protection are obtained mainly from the government health sector.

The number of disabilities a person has and the age of onset of disability are highly indicative of assistive device use. People with later onset of disability are more likely to be AD users than those with an early onset. The reasons for this require further analysis to understand. The most important factors in determining who is using an assistive device are race, age of onset and number of disabilities.

Disabled people who are AD users are more likely to receive a disability grant than not receive one, and if a disabled person receives a disability grant they are more likely to be an AD user than a non-user. This reflects a good link between services providing assistive devices and disability grants.

3.7 Summary on Education

As the chapter on education is a long one, it has been summarised for each section with an overall concluding section at the end. All the section summaries and conclusion section are included in this summary. The questions on education were only asked of respondents whose disability had started before the age of 18 and the sample size for this section is 787 respondents. Only the question on the highest level of education reached was asked of every respondent (i.e. N = 1703).

3.7.1 Summary and conclusions on school attendance

In this section we only asked where the disabled children were attending school. We did not ask any questions about the quality of education. The comments made on the quality of education are derived from other sources of information being applied to the statistics. For example, the high rate of school attendance at primary school age and the low school attendance at high school age suggests that the quality of education prevents disabled children from reaching high school.

The figures on school attendance indicate that primary school is the most accessible education level with 79% of respondents attending mainstream primary school and 12% special school, and only 5% not attending school at this level. Preschool and high school are generally not accessed well, with 40% and 44% of respondents attending mainstream schools at these levels respectively. A similar number of disabled children attend special schools for preschool and high school as for primary school (10% and 9% respectively).

This does not in any way mean that, just because many disabled children attend primary school in the mainstream system, that inclusive education has been achieved or that disabled children have been catered for. As pointed out by the National Commission on Special Needs in Education and Training and the National Committee on Educational Support Services (NCSNET/NCESS), this inclusion is an ad hoc solution which does not deal with the issues of special educational need nor disability. There just are no other services and so disabled children are on the whole 'dumped' onto the mainstream schools whether by their parents or the education system.⁷

The lack of ECD and early diagnosis and intervention services is reflected in the lack of attendance at preschool level (48%). Since this level of education has not been mandatory children are not sent to preschool especially where these services are scarce.

In relation to attendance at high school, the lack of attention to disabled children's special educational needs in primary school means that they do not often reach high school, and hence the rise in the 'not at school' figure for high school (47%). Similarly, the lack of special schools at the high school level adds to the number of disabled children who are out of school at high school level.

Vocational training is generally lacking as an available educational resource with 88% of respondents not attending this type of education.

As stated above, the data present an audit of attendance at the different types of schools with no assessment of the quality of education provided in the different types of schools. Some degree of

⁷ Some examples were provided during the feedback workshops to the provinces of instances where disabled children have been placed within mainstream schools and where the dedicated input from teachers and parents have made this a successful intervention. This is the exception rather than the rule, but provides useful indicators of what is possible.

quality assessment can be gleaned from the life stories and focus group discussions. Issues that need to be borne in mind when reading these results are the following:⁸

- The real concern is lack of provision in the mainstream. This provision has to be seen in the light of special schools which have traditionally captured most of the budget for special needs. Money that is used in the special schools is not spent on support for learners in the mainstream.
- The training of teachers is not only an issue for mainstream schools but also for special schools as is clearly demonstrated in the life stories and focus group discussions which indicated that teachers in special schools are not providing quality education.
- The dichotomy is not one of special schools versus mainstream but rather how to ensure the provision of quality education for all children including disabled children. At this stage in South Africa neither special schools nor mainstream schools provide this quality education.
- The high rate of attendance of disabled children at primary school could be slightly inflated by parents not wishing to admit that their children are not at school.

3.7.2 Summary of school attendance by age of onset

The earlier the onset of disability, the more likely a child is to attend a special school or be out of school and less likely the same child is to be attending a mainstream school. Of respondents with onset at birth, 66% attended a mainstream primary school compared to 96% of those disabled between the ages of 10 and 18 years. A similar pattern emerges for high school attendance where only 23% of respondents with onset at birth attended a mainstream high school, compared to 54% of those disabled between the ages of 10 and 18 years. The analysis did not consider the severity of the disability. It is possible that further research would show that the issue is not only one of the age of onset but also of the severity of the disability, where early onset also includes a high level of severity.

3.7.3 Summary of school attendance by type of disability

In summary, the pattern of school attendance by respondents whose disability started before the age of eighteen years reflects a number of different factors described below.

- The nature of certain disabilities makes it difficult for the child to benefit from schooling (see the high levels of 'no school attendance' for intellectually disabled children in high school - 82%);
- Communication and learning disabilities require relatively sophisticated diagnostic and assessment services to be identified. These services are more likely to be in the advantaged ('White') areas and the assessment tools are generally in English or Afrikaans. Children with these types of disabilities are more likely to be attending special primary schools (25% and 24% respectively) than children with other types of disabilities (range of 6% through to 16%). This is

⁸ These issues were raised by Downs Syndrome South Africa and the South African Federal Council on Disability, in response to an earlier draft of the report.

related to the finding (see below) that Whites are more likely to attend special schools than other race groups as they have had more access to these specialised services;

- There is a lack of accurate identification of disabilities which results in an ad hoc placement within mainstream schools with no real consideration of the child's needs;
- As the age of onset increases so children with moving around or daily life activities disabilities also join the ranks of those communication or learning disabled children who are most likely to 'not attend' school (i.e. be out of school).

These results should not in anyway suggest that special schools should be provided for all disabled learners. They merely describe the current school attendance patterns of disabled children.

The high figure for learning difficulties amongst those who did not attend school is consistent with figures cited by other policy investigations.⁹ In most cases learning difficulties were associated with a lack of attendance, failure or attrition.¹⁰ The figures for 'not attending school' could assist in providing disability prevalence amongst out of school youth.

Learners at a high school level seem to experience a range of difficulties. No or little provision exists at high school in South Africa for learners who are disabled and they are not provided with the necessary support. Besides making life extremely difficult for the learner who has special educational needs, this situation places additional strain on teachers who are struggling to cope with large classes. A support system in high schools is imperative for effective learning to take place by disabled learners.

The high 'not attending school' figures for children with communication (66%) or learning disabilities (71%) at high school level could be a result of lack of support for learners who experience difficulties in learning at this level.¹¹ The high percentage of non-attendance by intellectually disabled children (82%) supports the notion that no support exists at this level. Learners who probably would have benefited from support in a mainstream high school seem to find themselves in special schools or not at school.

3.7.4 Summary of school attendance by number of disabilities

The results suggest that having two disabilities makes one more likely to be identified as disabled and hence placed within a special school (12% at preschool and 14% at high school). On the other hand, having three or more disabilities makes one more likely to 'not attend school' (64% at

⁹ National Policy Investigation into Education Support Services, Oxford University Press, Cape Town, 1992. (NEPI)

¹⁰ The reader should note that a high proportion of children with intellectual disabilities would have also been identified as having learning disabilities according to the probe questions used in the survey.

¹¹ It should be remembered that many people identified as having an intellectual disability would also have been identified as having a communication and/or learning disability.

preschool and 67% at high school). The results for primary school attendance are not significantly different for different number of disabilities.

People with only one disability are significantly more likely to attend a mainstream high school (63%) than people with either two (35%) or three or more (24%) disabilities. People with two disabilities are more likely to attend a special high school (14%), and people with three or more disabilities are more likely to be 'out of school' at high school level (67%). The lower level of attendance at special schools by people with three or more disabilities could be indicating a trend to exclude the more severely disabled children from special schools.

3.7.5 Summary of school attendance by race

The main and significant differences across the four race groups are in the attendance at mainstream and special schools by African and White disabled children as well as differences in 'out of school' rates. Africans are more likely to attend mainstream primary schools (85%) than Whites (56%) and, conversely, Whites are more likely to attend special primary (32%) and high schools (33%) than Africans (8% and 5% respectively). Africans are also more likely to be out of school (51%) than Whites (11%) at high school level. These results highlight, firstly, that resources are more available in White areas, and, secondly, that the mainstreaming of African disabled children is not being done in a planned manner within an inclusive education system. It is rather an ad hoc solution to the lack of facilities. This should not be taken to mean that more special schools should be built, but rather that the training of teachers to work appropriately with disabled children in mainstream schools should be undertaken with urgency.

The high number of disabled children out of school at high school level could be reduced significantly if more resources were put into appropriate educational provision at preschool and primary school level.

The major concern, therefore, is that the majority of Africans are disadvantaged, and as a result of apartheid, seem to experience the most difficulties in education in both special and mainstream education. The funding formulae for schools that attempts to assist the poorest schools must take the disability issue seriously since the majority of learners who are disabled are in mainstream schools and are African.

3.7.6 Summary of highest education level reached

The results of a loglinear analysis show that the most important and statistically significant variables affecting the level of education reached by disabled people are age of onset and number of disabilities. The earlier the onset and the more disabilities a person has the more likely they are to have no education or to reach only primary education. The statistical differences obtained for these variables were highly significant. For example, only 13% of respondents with one disability had no education, while 38% of those with three disabilities had no education. Respondents with age of onset before two years of age are most likely to have no education (30%) compared to only 11% of those with onset between 3 and 18 years, and 15% of those with onset between 18 and 65 years of age. Other variables such as race, type of area and type of disability do not have as significant an impact on the education level reached. The main factor in determining level of education reached is clearly the disability. This effect is then compounded by factors such as race, type of area and type of disability.

3.7.7 General conclusions on education

This summary highlights some of the more important conclusions arising from the data analysis.

The results of this survey to a large extent support the findings of other national policy and research initiatives concerning disability and education. Generally, these findings suggest that the area of disability is a very neglected area and should be targeted as a redress issue. Rural African people are the worst affected sector of the disabled population. The findings of this survey have major implications for inclusion, support for learning and curriculum planning, teacher training, human resource development, general resources for the school, funding of schools vocational training and the creation of employment opportunities. The point of departure in addressing the above issues must recognise that the majority of learners are being taught in mainstream schools.

The establishment of more special schools does not provide a solution to providing educational services to disabled children, despite the views expressed by respondents on this issue, (i.e. that special schools are what is needed for disabled children to reach matric, and so on). Special schools, firstly, absorb a large proportion of the budget to serve a few disabled children; secondly, they do not facilitate the integration of disabled children into society; and, thirdly, the education they provide leaves much to be desired as was eloquently described in the life stories and focus groups earlier in this report. So, even if there were enough resources to provide special schools for all disabled children it would not be the route of choice within a human rights framework which aims to facilitate the integration of disabled people.

The low special school provision in a country that has a dual education system (special and mainstream education systems) precisely underlines the biggest reality of the developing world, namely that one could never build enough special schools to answer the need of all disabled learners. The duality of the system just makes the problem worse, as it is providing a disproportionate level of support to a very small number of learners (who are seldom the most

needy) while the largest majority have no services at all. It is widely accepted that dual systems are the least cost-effective systems. As long as you maintain a dual system you will never be able to provide enough support so as to make the mainstream more inclusive.¹²

The results of the survey together with information from the life stories and focus groups highlight the fact that neither the special nor the mainstream educational systems provide effective education for disabled children. What emerges clearly out of the survey is that there is a need for support and that it must be provided by the system wherever learners find themselves. The finding that many respondents see special schools as a viable and important option for assisting disabled children to reach matric, should be looked at further in terms of awareness raising around the issue of inclusive education, budgets and the aim of integrating rather than marginalising disabled people within society.

3.8 Summary on employment

All respondents who were 15 years or older at the time of interview were asked the questions on employment. The total sample size for this section is 1448 out of the 1703 sample of disabled people.

The data on employment indicate that race, sex, number of disabilities and age of onset all play a significant role in whether a person is employed or not. Whites are more likely to be employed, women are less likely to be employed, and people with more than one disability or who have an early onset of their disability are all less likely to be employed. The overall employment figures are low at 12%¹³ being less than a third of the employment rate for the general population. Of the total number of disabled people 15 years or older, 88% were economically inactive and/or unemployed but looking for work compared to 63% of people in the general population in a similar position. These data indicate that disabled people face serious barriers to employment.

Nineteen percent of White disabled people are employed in a full-time position compared to Africans (6%), Coloureds (4%) or Indians (9%). The employment rates for disabled women is 11% compared to 15% for disabled men and 80% of disabled women are economically inactive compared to 74% of disabled men.

Of the respondents with age of onset before 2 years of age, a mere 7% are employed and 87% are economically inactive compared to 17% of those with age of onset between 19 and 65 years who are employed and 71% who are economically inactive. Of people with one disability, 18% are employed and 70% are economically inactive. In comparison, only 6% of people with three or more disabilities are employed and 87% are economically inactive.

¹² Comments provided by Downs Syndrome South Africa on an earlier draft of this report.

¹³ This includes people who are employed full-time and part-time or who are self-employed in the formal or informal sector. If we look at the number of people who are employed full-time, we see that 19% of Whites, 9% of Indians, 4% of Coloureds and 6% of Africans are employed full-time.

Further research is required to provide more detailed information on the type of jobs people do, the issue of sheltered employment and differences between employment of men and women within the four race groups. The sample size of employed people was too small to allow for these issues to be investigated sufficiently.

3.9 Summary on transport

All respondents were asked about the main form of transport they use as well as what they think would be the best form of transport to provide for people with disabilities. No questions were asked about the frequency of use and the accessibility of the transport used.

The data show that:

- The majority of respondents make use of public transport but with no indication of whether this type of transport is accessible or not;
- The majority of respondents think special transport is the best way to provide transport for disabled people; this result could be seen to indicate that the public transport system is so inaccessible that the only solution to provide transport is through special transport;
- Respondents in rural areas are more dependent on public transport than respondents in urban and metropolitan areas;
- More advantaged respondents are more likely to make use of cars as their mode of transport.

Further research is required to complement the survey data. This would include looking at the accessibility of public transport and the frequency of use by people with different disabilities.

3.10 Summary on accessibility of the environment

All respondents were asked whether their home (rooms and toilet) and various public places were accessible.

The results indicate that accessibility was narrowly understood to only mean physical accessibility. This may be why mostly people with moving around, movement activity and daily life activity disabilities said that they found their environment often inaccessible. Hospitals and primary health care clinics were the places that were most accessible to people with disabilities no matter what their disability.

It is also evident that accessibility is not much of an issue for the other types of disabilities or it is so much of an issue that the person just does not go to these places (e.g. people with communication disabilities not accessing public places because they cannot make themselves understood). If someone never goes to a place, they are never confronted with accessibility issues. This does not mean these places are accessible.

Further research would, firstly, need to look at whether people would want or need to go to these various places, how often and what they felt would make those places more accessible.

Secondly, a more detailed interrogation of different aspects of a building (e.g. toilet, entrance, floors other than ground floor, signposts, use of braille, etc.) would provide a comprehensive complement to the survey data.

3.11 Summary on social security

All respondents were asked whether they receive a state grant or pension (e.g. disability grant, care dependency grant, grant-in-aid, old age pension, etc.) or another pension (e.g. private insurance, workmen's compensation, etc.). If they received one they were asked what they receive and how long it took to start receiving it after applying for it and what the money is mainly spent on. The data were analysed separately for non-pensioners (women younger than 60 years and men younger than 65 years) and pensioners (women 60+ years old and men 65+ years old).

The data indicate the following:

- Of all the disabled people who are non-pensioners, 68% are *not* receiving a grant or private insurance pension and 32% *are* receiving a grant or private insurance pension. Disability grants are the most common type of grant for non-pensioners (over 80% of grants are disability grants).
- Of the disabled respondents in our sample who are eligible to receive pensions based on their age, 78% are receiving a pension and only 22% are not receiving a pension.
- Respondents in Kwazulu-Natal (71%) are more likely than respondent's in all the other provinces to receive disability grants. Respondents in Mpumalanga (33%) and Gauteng (47%) are less likely to receive disability grants.
- With regard to old age pensions, respondents in Mpumalanga (50%) are more likely than respondents in all the other provinces to receive an old age pension and respondents in the Northern Cape are the least likely (9%) to receive old age pensions.
- Coloured respondents (53%) are more likely than any other race to receive grants or private insurance pensions and Africans respondents (29%) are less likely than any other race to receive grants or private insurance pensions.
- Respondents with a hearing disability (33%) and learning difficulties (37%) are less likely to have applied for a grant and they are less likely to have received a grant than people with any other disability.
- Respondents with a movement activity disability (63%), moving around disability (63%) and daily life activity disability (64%) were all more likely to have applied for a grant and they were also marginally more likely to be successful in their application.
- Almost half of the respondents (46%) said that they waited between 3-12 months for their disability grant. Twenty seven percent waited three months or less and about 21% of respondents waited longer than a year.
- Respondents with more than one disability are more likely to receive a grant than the respondents with only one disability. Within the number of disabilities sex seems to have an effect. Males with a single disability are more likely than females with a single disability to

receive a grant. However, generally respondents with multiple disabilities are more likely than respondents with a single disability to receive grant/s.

3.12 Summary on participation within family life

As for the summary on education, this section presents the summaries for each section and ends with a general chapter summary and conclusions. In this section all respondents were asked about their level of integration within the family, how they feel about being disabled or having a disabled child, how they would like society to treat them or their disabled child and what they would ask the president to do to improve the lives of disabled people. The level of integration or participation within the family was calculated using responses on five questions.

3.12.1 Summary of level of integration within the family

There are a number of factors that are important in determining whether a person experiences high, medium or low levels of integration. A loglinear analysis was undertaken to determine which of these are the most important. The results show that age of onset and number of disabilities are the two most crucial variables determining the level of integration of a disabled person within his or her family. The earlier the onset and the greater the number of disabilities, the less integrated the person is likely to be within their family. The later the onset and the less the number of disabilities, the more likely the disabled person is to be integrated within their family. Of respondents with one disability, 67% had a high level of participation compared to 49% of those with three disabilities or more. Of respondents with age of onset before two years of age, 41% had a high level of participation compared to 66% of those with age of onset after 19 years of age.

These two factors override the effects of race, type of disability and sex in determining level of integration. These findings highlight the overarching disadvantage caused by being disabled no matter what race or sex a person is nor the type of disability the person has. When disadvantage due to race is added onto being disabled (i.e. African disabled people), the discrimination is further increased or aggravated.

Further research is required to determine whether age of onset and number of disabilities impact in the same way on the level of integration within broader society, or whether in broader society the effects of race and sex become more prominent.

3.12.2 Summary of 'feel' words used by respondents

These results are of the words used by respondents to describe how they feel inside about their disability or their disabled child.

- Of the respondents who answered the question on how they feel about being disabled or having a disabled child, 59% used negative words, 21% positive words, 8% discrimination words and 12% other words. If we add the discrimination words to the negative ones, we see that over two thirds of respondents gave negative type words to describe how they feel.

- People with early onset of disability were less likely to use a negative word (53%) than those with later onset of their disability (62%). People disabled in old age were most likely to use positive words (30%).
- The variables of sex, number of disabilities, direct and proxy reporting and type of disability did not have any effect on the words used by the respondents. In other words, men and women used ‘feel’ words in the same manner, as did people with different numbers of disabilities, and so on.
- If a person had received educational services, they were more likely to use a negative word than if they had not received this service. The reasons for this require further research.

3.12.3 Summary of how society should treat disabled people

- Just under two thirds of people mentioned the need to be treated ‘like normal people’ or with equality. This result suggests a high level of awareness of being different and the desire to be part of regular society.
- Disabled people living in metropolitan areas are most likely to want society to treat them equally (66%), while disabled people living in rural areas are most likely to want society to treat them nicely (33%). However, a note of caution is warranted here. It seems that in many Bantu languages the words for ‘nicely’ and ‘equally’ could be the same or very similar. Hence, the word ‘equally’ could have been translated as ‘nicely’ The effect of this would be to merely increase the number of people who used the word ‘equally’.
- A greater proportion of people with one disability (68%) asked for society to treat them equally than people with three or more disabilities (58%). The reverse was true for people asking to be treated nicely: a greater proportion of people with three or more disabilities want to be treated nicely (32%) than those with one disability only (21%).
- The variables of age of onset, sex, type of disability and direct or proxy reporting did not have any significant effect on how the respondents wanted society to treat them or their disabled child.

3.12.4 Summary of what the President should do to improve the lives of disabled people

- The single most common response was to ask for special care and services (20%). A combination of the categories of finance, social assistance and handouts/groceries shows that 30% of respondents expressed a need for direct assistance by the state. A combination of the categories of equality, work, laws to empower, accessible buildings and services yields a response rate of 40% of respondents. This does suggest that many respondents were clear about what needs to happen in society in order for disabled people to be integrated and empowered.
- That respondents with early onset of disability are more likely to want special care and services (25%) than people with later onset of their disability (16%). People who became disabled between the ages of 19 and 65 years are more likely to want social assistance (11%) than other age of onset categories.

- Fourteen percent of disabled people in rural areas requested financial assistance of some form, whereas only 9% of metropolitan dwellers requested this. The metropolitan dwellers were more aware of the need for equality as 13% of them requested this as opposed to only 7% of rural dwellers. Of the metropolitan dwellers 11% wanted work whereas only 6% in rural areas asked for this.
- Proxy reporters were more likely to request special care and services than direct reporters. Direct reporters were more likely than proxy reporters to request 'equality'.
- The variables of sex, type of disability and number of disabilities did not have any significant effect on what people would ask the President to do to improve the lives of disabled people.

3.12.5 General summary and conclusions for the chapter on participation within family life

This section will highlight a few concluding remarks.

In relation to integration or participation within the family, it is clear that the age of onset and number of disabilities a person has are crucial in determining the extent of integration. These factors are more important in creating a difference in level of family integration than even race and sex of the respondents. Whether this trend will also apply to the level of integration or participation within broader society is something requiring further research.

The sex of a person is not a statistically significant factor in determining what the disabled person feels, how they would like society to treat them and what they would ask the President to do to improve the lives of disabled people. How one feels as a disabled person could be determined by factors such as education and employment, which are crucial in facilitating integration of disabled people into broader society. The chapter on employment did find differences between men and women in terms of employment status.

Similarly, the type of disability a person has does not influence the way the person feels, how they would like society to treat them or what they would ask the President to do for disabled people. This suggests that the varying effects of factors such as education, employment and access to services (which often did show differences between the different types of disabilities) all culminate in similar results of how someone feels about being disabled.

This section presents quantitative findings on how people feel, want society to treat them and what the President should do to improve the lives of disabled people. More research is needed to provide a further understanding of how the significant factors do interact in determining the level of integration within the family as well as within broader society.

4 CONCLUSIONS

It is difficult to end this report with one concluding section. There are so many different aspects to the data and so many ways to use it that to try and summarise these in a conclusion seems too limiting. Each chapter has its own summary of the main findings and some interpretation of these within the main body of the chapter. It is up to the reader to make their own conclusions and apply these conclusions to policy formulation and implementation, with a good understanding of how to use statistical data.

Whoever uses the data should take responsibility for how they use the data. They must be prepared to clearly justify their interpretation of the data and the way they plan to use the data.

This survey project has provided somewhat of a watershed in an ongoing process of research on disability. The results have provided much to ponder on and the process of the research has highlighted a number of issues around doing research in disability that should be borne in mind by both researchers and the disability sector in the future.

The national baseline disability survey has successfully provided a baseline measure of moderate to severe reported disabilities in South Africa at the end of the Twentieth Century.

The results in some instances provide important pointers to what needs to be provided. In other instances, they provide a framework for a more detailed data collection and analysis. The nature of a large national survey is such that compromises have to be made in the number of questions that are asked and the detail in which they are asked. The pay off is a wide range of areas that can be tapped. This survey provided that wide range of information which can now be developed further in more local, regional provincial surveys or in surveys looking at specific types of disabilities. There are also a number of areas that were not investigated such as issues of violence against disabled children and women, integration within broader society, and so on.

This section highlights some examples of these different aspects of the data and then goes onto reviewing the questions that were posed in the Introduction chapter of the full report and see how the data can answer these questions.

4.1 Examples of information that can be used for planning immediately

The following are some of the more obvious examples of information that can be used from the survey.

- The causes of disability provide information on preventive services that need to be put in place to limit the incidence of these disabilities; examples are the high rate of illnesses such as hypertension and diabetes causing disabilities, the high rate of disabilities due to birth trauma in the rural areas, and so on.

- The severity chapter provides compelling data on the effect of providing assistive devices and/or personal assistant services. An economic analysis of the cost effectiveness of providing assistive devices and personal assistants would be a useful complement to the data in developing motivations for developing these services to a larger extent.
- The chapter on services needed and received are a clear testimony to the lack of services in many areas. The results give information on the type of services to be provided and a means of measuring progress in the provision of these services through comparison with the baseline data on services needed and received.
- The education chapter provides information on school attendance and highlights the gaps in preschool and high school educational provision. Although the data does not deal with issues of quality of education, it does provide important baseline information against which to measure success of educational intervention programmes. If these are successful for example at preschool and primary level, the attendance figures for high school level should increase as more disabled children are provided with the required support to pass onto high school. The figures for 'out of school' disabled children should also decrease with improved education services.
- The employment chapter provides useful baseline information on employment rates and rates for unemployment for disabled people who are not economically active. The success of interventions such as the Employment Equity Bill can be measured against this baseline data.
- Throughout the report, responses to opinion-type questions provide interesting and useful information on what many disabled people are thinking. This information is crucial if policy developments (e.g. like inclusive education) are to be successful. These opinions and perceptions must be taken into account in awareness raising campaigns and information provision.
- The chapter on integration of the disabled person within the family provides data on the current views of disabled people about their situations. Success of interventions can be measured against these data. This chapter provides a baseline measure of what disabled people are feeling about their situation. What would be of interest in the ongoing monitoring and evaluation of interventions is the impact of these on the way disabled people feel about being disabled.
- The obvious disparity between the experience of disability (education levels, employment rates, words used to describe how a person feels) for African disabled people in relation to particularly, White disabled people is another clear area of intervention highlighted by the survey.

4.2 Examples of information that require further research to complement the survey data.

These are some of the more obvious examples of where further research is required to complement the survey data before they can be used effectively.

- Accessibility and transport issues need to be looked at further including data that is more disability specific to provide the individual experience that does not come out in the

aggregation of all disability experiences within the total population of the country. The survey data highlights the fact that accessibility remains an important problem. More disability specific information provides a good understanding of how to improve accessibility. The organisations of disabled people have over the years compiled much of this information already.

- The issues of type of employment and levels of income in relation to employment would be information required to complement the chapter on employment.

4.3 Answers to questions posed in the introduction

Questions were asked in the introduction of the full report. This chapter now concludes by attempting to answer these in relation to the findings of the survey.

The questions posed in the Introduction are presented in italics and the answer provided by the survey data follow each question.

- *Is a rural African person with a disability at a greater disadvantage than an African person with a disability in an urban or metropolitan area because of lack of services in the rural areas?* There do not seem to be significant differences in the access to services in urban or metropolitan areas and rural areas for African disabled people generally. This suggests that services for African disabled people are generally very poor, no matter where they are provided.
- *Are women with disabilities discriminated against more than men with disabilities as indicated by lower level of education and less likelihood of being employed?* The only significant difference arose in the employment figures. This reflects similar differences between men and women within the general population. The overriding disadvantaged experienced by the respondents was their disability. This then sublimated to some extent other disadvantages due to sex. If we had investigated issues such as violence against disabled people, we might well have found a significant difference in the experience of disabled men and women.
- *Are white disabled people less disadvantaged than African, Coloured and Indian disabled people because of having better access to services and resources?* The issue of access to services does seem to have a significant effect on the disability experience. Better education and rehabilitation services do seem to have an impact on a person's ability to find employment. Coloured and African respondents were both more disadvantaged than Indian and White respondents.
- *Do people who are disabled at an early age have a different experience of disability compared to those people disabled in adulthood?* There is a significant difference both in terms of education and employment, as well as in the way these two groups of disabled people see their disability. People with early onset of disability are less integrated within the family but more likely to use positive words about how they feel than people disabled later in life. It should however, be remembered that the majority of respondents used negative words

to describe how they feel. The small proportion who did use positive words tended to be people with early onset of disability.

- *What is the experience of disability due to old age?* The effects of old age are that disability occurs more frequently, that the use of assistive devices increases with age but that people who are disabled because of old age are still integrated within the family.
- *Is the number of disabilities or activity limitations a person has a significant factor in determining their experience of disability?* Yes, the number of disabilities a person has does impact significantly on education, employment and integration. However, it does not have any effect on how a person feels about themselves.
- *Are the cause and type of disability significant factors in determining the experience of disability?* In some instances such as education and employment, access to home and public facilities, the impact of the different types of disabilities is clearly different. In other aspects, such as how a person feels, it does not have a significant impact. The cause of the disability to some extent determines the type of disability and hence has similar effects as the type of disability.

The conclusions reached above are only valid for those parameters that were investigated in the survey as listed in the description of the areas covered in the questionnaires as well as the factors considered in the analysis.

The answers given above suggest that the divisions in society happen along lines of, firstly, disabled and non-disabled, followed only then by divisions along sex and race (advantaged and disadvantaged), and so on. The first criterion to apply would seem to be whether someone is disabled or not. The criteria to consider after that are the sex and race of the person in the same way that these factors would be considered in the non-disabled population.

This explains why the survey does not pick up significant differences between men and women in almost all major aspects except employment. This does mean that if a person is disabled, a woman and African the chances are higher that she would be less educated (because of being African) and less likely to be employed (because of being a woman) than a White man who is disabled. Both of these people would however, be less educated and less likely to be employed than both their non-disabled counterparts because of being disabled.

The efforts in place to overcome sex and race discrimination should also impact on disabled people. However, the ongoing efforts to overcome discrimination on the basis of disability remain a major priority.

APPENDIX A

Probe Questions for screening questionnaire

INSTRUCTION:

Please note that all questions refer to both the respondent and the members of the household including very young children. These questions are not for coding. They are to help you to mark the correct disability. Every disability that comes up as a yes in these probes must be marked in question 3.3

1. Seeing

Is anyone in your household blind in one or both eyes ?

1.2 Does anyone in your household have difficulty in...

seeing ordinary newspaper print at arms length even when wearing glasses or contact lenses, if usually worn?

recognising a person you know across the road?

recognising a person you know across the room?

recognising an object at arm's length?

2. Hearing

2.1 Is anyone in your household deaf in one or both ears?

2.2 Does anyone in your household have difficulty in ...

understanding what is said if someone is talking on the other side of the room?

hearing what is said in a conversation with another person, even when wearing a hearing aid?

hearing what is said over the telephone with or without a hearing aid?

3. Communication problems (speaking, being understood & conversing with people)

3.1 Does anyone in your household have difficulty in speaking or being understood (e.g. stuttering)?

3.2 Does anyone in your household have difficulty in ...

generally understanding what people say?

making themselves understood?

starting or maintaining a conversation?

4. Movement activities

4.1 Does anyone in the household have a physical disability?

4.2 Does anyone in the household have difficulty in...

standing up from sitting down?

getting up from lying down?

picking up things with their fingers?

opening containers?

sitting for long periods (20 minutes)?

standing for long periods (20 minutes)?

turn from lying on their back to lying on their stomach?

bending down and picking up an object from the floor?

dressing and undressing?

getting in and out of bed?

cutting their own food?

5. Getting around or moving around

5.1 Does anyone in your household have difficulty in...

getting around the home?

walking around their neighbourhood?

going up or down two steps/flight of stairs?

getting out of the home?

using public transport?

moving from one room to another?

6. Daily life activities

6.1 Does anyone in your household have any difficulty in...

washing their face?

washing their whole body?

getting to and using the toilet?

feeding themselves?

Is anyone in your household completely unable to do household work/responsibilities/tasks/chores because of their disability? (e.g. cleaning, cooking, caring for children and animals etc.)

7. Intellectual disability

7.1 Is there anyone in your household with Down Syndrome or any other mental handicap (intellectual disability)?

7.2 Is there a young child in your household who is slow in developing (walking, talking etc) compared to other children of the same age?

7.3 Are there any older children or adults in your household who were slow in developing (walking, talking etc) compared to other children or adults of the same age?

8. Learning difficulties

8.1 Has anyone in your household had problems with learning or keeping up with the rest of the class? (e.g. child has repeated the same grade/standard two or more times)

8.2 Is there anyone in your household between the ages 6-16yrs who is not attending any school?

8.3 Is there anyone in your household who is three or more years older than the expected average age for that class? (e.g. if the average age for grade 5/standard 3 is 10 years, and the child is 14 years old)

8.4 Has anyone in your household attended in the past or is currently attending a special school or a special/adjustment/bridging class in a regular school?

8.5 Does anyone in your household have or had difficulty in...
concentrating on something?
paying attention to something/someone?

9. Emotional disorders (psychological and psychiatric)

9.1 Does anyone in your household have behaviour that is out of the ordinary or that changes or has changed? (e.g. personality changes, hears voices, disoriented, depression, phobias or obsessions)

9.2 Has anyone in your household visited a psychologist, psychiatrist, counsellor or traditional healer recently or in the past because of an emotional or psychological problem for more than three months?

9.3 Is anyone in your household on psychiatric medication?

9.4 Does anyone in your household have difficulty in...

co-operating with people?

making new friends?

controlling their temper when they are with others?

controlling their feelings when they are with others?

maintaining close personal relationship with friends and peers?

controlling their anxiety?