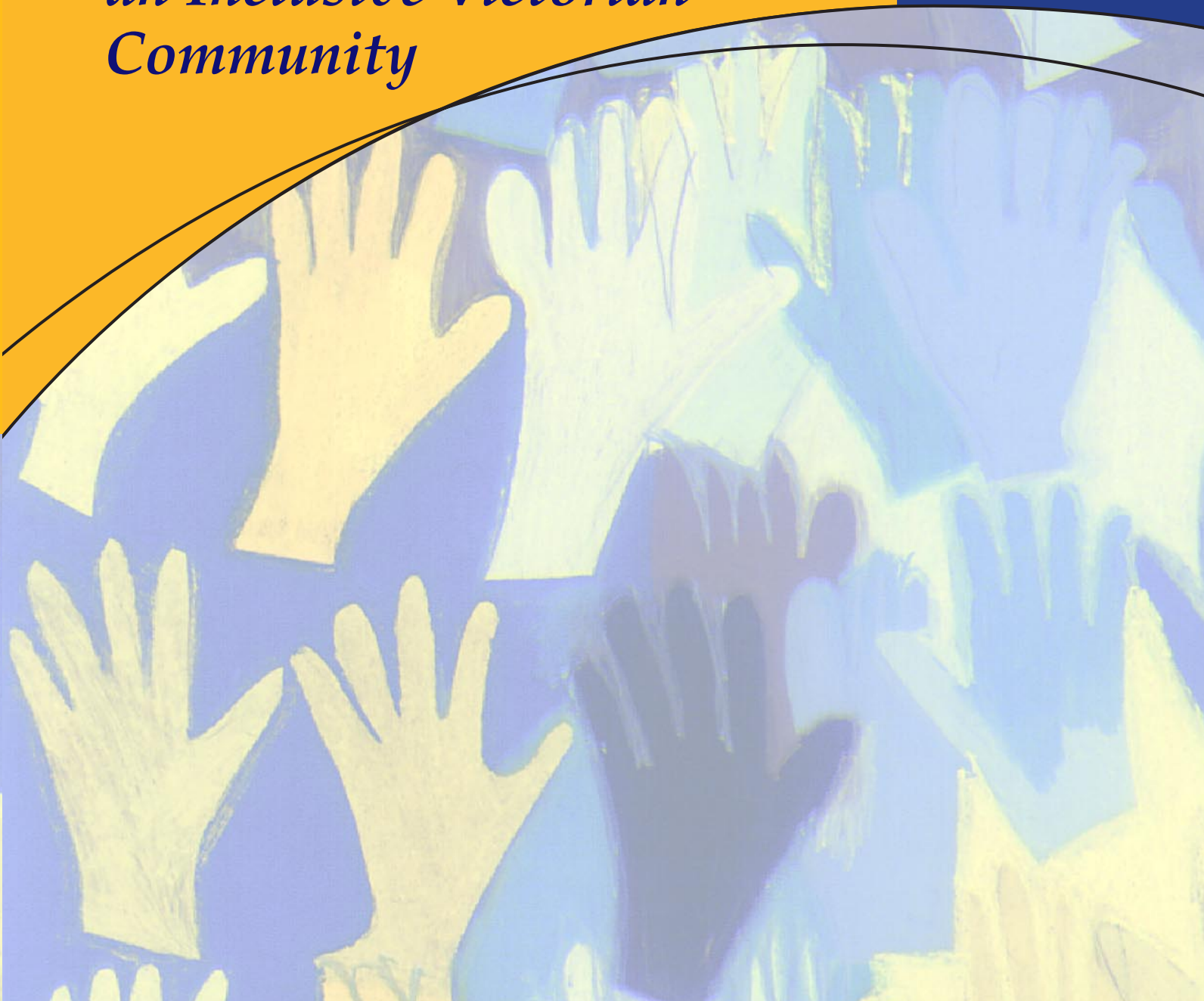


The Aspirations of People With a Disability Within an Inclusive Victorian Community

Human
Services



Peoplefirst



Summary Report

DisAbility Services



The Aspirations of People with a Disability within an Inclusive Victorian Community

Summary Report

**DisAbility Services Victoria
Department of Human Services**



Further Information

This report is available at the DisAbility Services Division Internet address:

<http://www.dhs.vic.gov.au/disability>

If you require additional copies of this report or have any queries please contact DisAbility Services on (03) 9616 8427.

This publication is copyright. No part may be reproduced by any process except in accordance with the provision of the *Copyright Act 1968*.

Published by Performance, Planning and Research, DisAbility Services, Victorian Government Department of Human Services.

0671100

Acknowledgements

This report was prepared by Jeannette Johnson of Millward Brown, Australia, October 2000.

We are grateful to the disability advocacy groups that helped with the distribution of information and promotion of the project. In particular we thank Michael Gourlay of Association for Children with a Disability, Steve Blair of Disability Rights Victoria and Kevin Stone of VALID who assisted with strategic advice and planning of this project. We thank the many disability groups and service providers who provided their offices for the conduct of the group discussions.

The author would like to thank Mirella Danelutti, DisAbility Services Victoria, for her valuable assistance and support throughout the project.

Jeremy Brewer and Mandy Reed of Red Cross Australia recruited and helped train a number of the interviewers for this project and Mandy undertook the literature review. The Millward Brown team worked together to bring the project to fruition; Jasmine Hoye, Kay Colquhoun and Susan Morgan-Ellis were integral members of the team and made strong contributions to its success.

Finally, we express our thanks to all of the people who participated in the focus group discussions and the face-to-face interviews and openly discussed their dreams, hopes and aspirations for the future.

Cover artwork *Hands* (1998) by Julian Martin courtesy Arts Project Australia Inc.

Contents

Introduction	7
Background	9
The Context of Disability	12
Quality of Life	16
Current Activities	18
Aspirations	20
Attitudes towards Disability	27
Conclusion and Challenges	31

Introduction

The Victorian State Government has underlined its commitment to an inclusive society for all people in Victoria. As part of its Community Services policy, the Government is developing the State DisAbility Services Plan, covering services for people with intellectual, physical and sensory disabilities, acquired brain injury (ABI) and neurological impairments. The project titled 'The Aspirations of People with a Disability within an Inclusive Victorian Community' was designed to provide a voice to the goals and aspirations of people with a disability and, in so doing, inform the Plan's development.

I am committed to ensuring that within the Victorian community, people with disabilities are on a level playing field with all other Victorians—I want them to have the same opportunities that many of us take for granted: the opportunity to participate, to contribute and to be included in all facets of community life.

[Minister for Community Services, the Hon. Christine Campbell]

The project involved more than 500 people with disabilities, including parents of children with disabilities and carers of adults with disabilities. A wide range of people from all walks of life participated in the study, providing a rich array of views and experiences as well as their hopes for the future. While the findings should not be extrapolated to all people with disabilities, the views and opinions expressed by the study participants provide a valuable insight into the experiences of people living with a disability in Victoria. The study confirms that people with disabilities do not comprise a homogeneous group but include a diverse range of people.

The findings of this study will make an important contribution to the development of the State DisAbility Services Plan. The project report will also be used by the DisAbility Advisory Council in their work with the Victorian community. In addition, the study will assist in the development of policies that may affect people with disabilities across departmental boundaries. Perhaps most significantly, the study provides evidence of the importance of working in partnership with people with disabilities as members of our community.

Background

Like all members of the community, people with disabilities aspire to have close and loving relationships, to be valued as members of their community and to experience physical and material wellbeing.

For people with disabilities this may mean they will require additional support, sometimes of a specialised nature, to assist them to meet these goals. The services the Department of Human Services funds and operates should, therefore, assist people to strive for their goals.

To plan and develop the type of services needed to support people with disabilities and to further include them in the life of the Victorian community, it is necessary to gather information from a number of sources. The most important source is people with disabilities themselves. A significant question that can be asked of people with disabilities is: what is the kind of life you hope to have? And for the parents of children with disabilities: what is the kind of life you hope your child will have?

To define people with disabilities as **service users**—as has often been the case in the past—is to define them by only one aspect of their lives. The Aspirations of People with a Disability within an Inclusive Victorian Community is a research study that is concerned with the totality of people's lives—what they enjoy doing, what the barriers are, what they want for the future and how they see themselves getting there. This articulation of the hopes, needs, concerns and aspirations of people with disabilities is fundamental to ensuring that services are funded and planned around **people** rather than around **service users**.

The purpose of the project was defined simply to describe the aspirations of people with disabilities. To achieve this, the project sought to gather the views of a broad range of people with disabilities from all aspects of the Victorian community, including the families and carers of children and adults with disabilities.

In April 2000, Millward Brown Australia (MBA) was contracted to undertake the research. The people responsible for the project were Jeannette Johnson at MBA (principal researcher) and Mirella Danelutti in the Department of Human Services.

This report provides a summary of the project aims and findings and has been derived from the detailed final project report.

Method

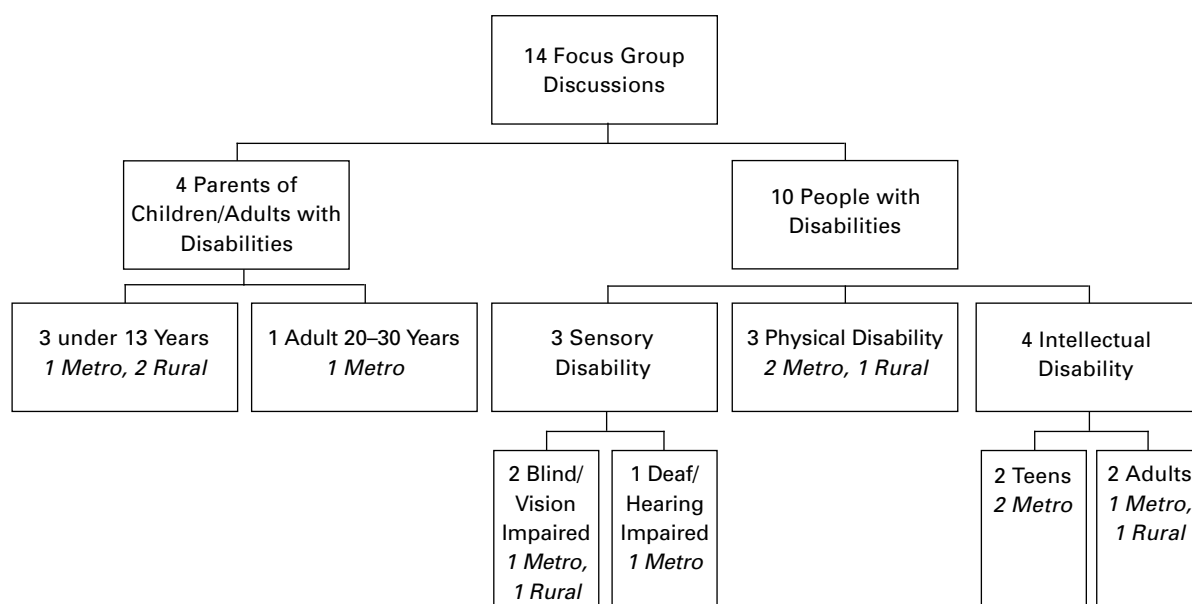
A range of research tasks were required to complete the study including a literature review, a series of in-depth interviews with advocacy groups and service providers representing the range of disability types, focus group discussions and face-to-face interviews. The information summarised in this report was derived from 14 focus group discussions and 444 face-to-face interviews with people who have a disability.

The Focus Group Discussions

Focus group discussions provided an opportunity for deeper analysis and exploration of issues to be canvassed in the face-to-face interviews. While the latter gave a measurement of specific goals and aspirations, the focus groups allowed us to probe the reasons underlying attitudes. In addition we were able to explore the context of living with a disability (or parenting a child with a disability). Participants in all of the focus groups were recruited with the assistance of advocacy groups and service providers.

The composition of the focus group discussions is summarised as follows:

Figure 1: Composition of Focus Groups



The Face-to-Face Interviews

The purpose of the face-to-face interviews was to obtain a quantitative measure of the goals and aspirations of people with disabilities, as well as steps taken towards achieving their goals and the barriers.

The in-depth questionnaire utilised a descriptive approach, asking open-ended questions relating to current activities enjoyed and future goals and aspirations, as well as barriers likely to impede these. The final section of the interview asked participants to rate their practical and more personal goals and explored attitudes towards disability.

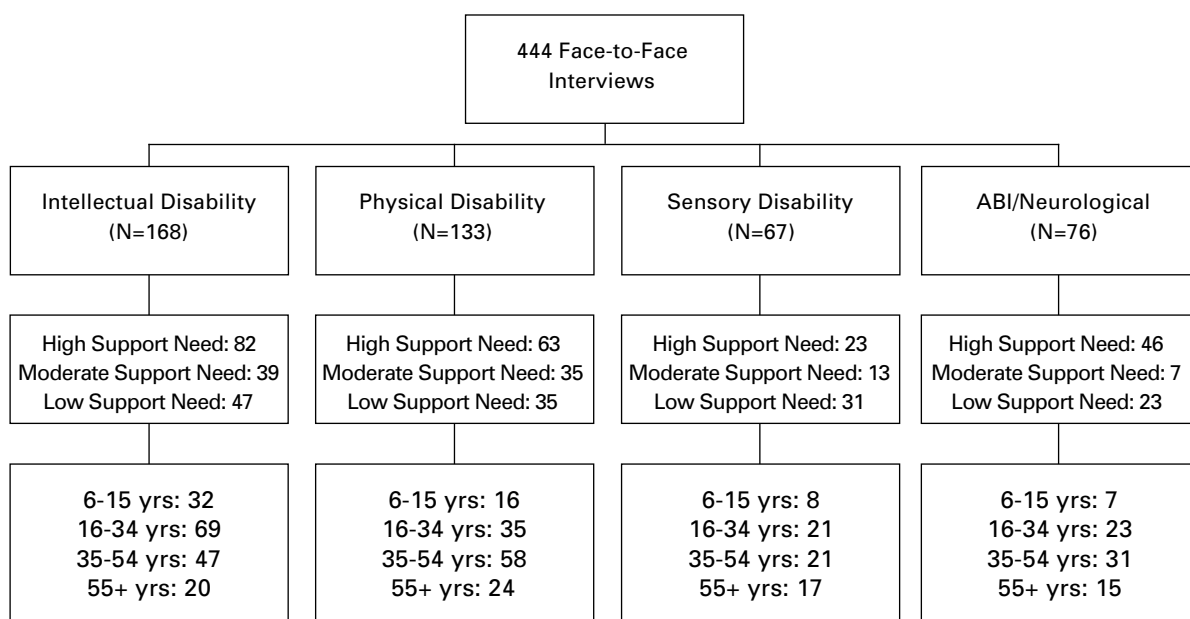
A key methodological concern for the face-to-face interviews was to ensure that participants were drawn from a broad range of people with disabilities as set out in the Victorian *Disability Services Act 1991*. To this end, a range of mechanisms for promoting the study were instituted including a series of mail-outs by service providers and advocacy groups that had agreed to assist. Additionally, radio and personal promotion of the study was undertaken as well as other mechanisms to encourage participation. Information was sought from interested respondents via a screening interview about a range of factors including disability type, level of support

needs, gender, age, location and any communication needs. Appointments were then made for the personal interviews.

The final sample structure for the face-to-face interviews is shown below. To ensure a wide cross-section of the views of people with disabilities, it was sometimes necessary to interview the respondent with the assistance of a carer or someone else. Sixty-five per cent of interviews were conducted with the person with a disability aged 16 years or above; 21 per cent were conducted with the carer of an adult aged 16 years or above with a disability and the person with a disability (either assisting the person with a disability to participate in the interview or responding on their behalf); and 14 per cent were conducted with the parent of a 6–15 year old with a disability.

Slightly more males than females were interviewed: 54 per cent males and 46 per cent females. The interviews were split between metropolitan Melbourne (55 per cent) and rural Victoria (45 per cent) and a spread of age groups was covered. The vast majority of respondents (68 per cent) lived at home, either alone or with family; 4 per cent shared a house with friends and the remainder (27 per cent) lived in either a group home, a hostel or larger setting for people with disabilities. The sample included approximately 10 per cent who were from a non-English speaking background and 4 per cent who identified as Aboriginal or Torres Strait Islander peoples.

Figure 2: Composition of Final Sample Face-to-Face Interviews

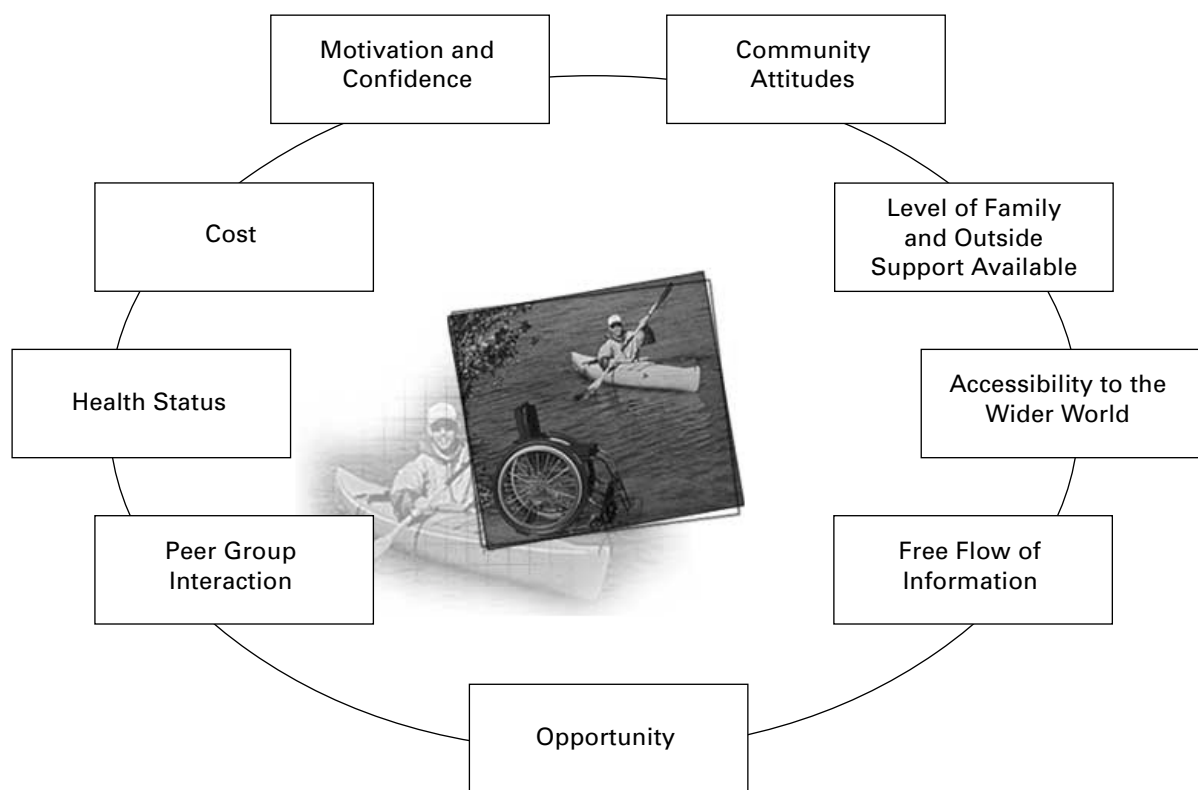


The Context of Disability

In seeking to understand the aspirations of people with disabilities—how aspirations are formed, their nature and their likelihood of achievement—it is first necessary to examine the context of the lives of people with disabilities.

The focus group discussions confirmed that there are many influences on an individual's experience of disability. Through the focus group discussions a number of factors were seen to emerge. These factors included the following:

Figure 3: Factors Influencing Experience of Disability



Motivation and confidence

It is unrealistic to expect that **all** people share the same level of drive and ambition. Factors that appear to have an influence are age, confidence, 'coaching' from family, friends and other support people, curiosity, individual circumstances and experience.

I was always very independent, but no longer. I think I may be able to do it, I just have to take that first step.

[Young woman recently diagnosed with a vision impairment]

External coaching—by self-advocacy facilitators, role models, parents, providers of disability services, teachers and siblings—appears to have a marked influence on attitudes to future possibilities. The necessity to take the first or the next step may be recognised, but often an external impetus is needed to impel action. As stated, and as could be expected in the general population, people with disabilities who are getting older often tend to narrow their perspectives; this can be confounded by negative experience.

I don't look that far in the future, I just take it day-by-day because in the past I have looked into doing things and they have never come off, so now I just take it day-by-day.

[Middle aged man with a physical disability]

Community attitudes

It is believed that, today, community attitudes are slowly becoming more positive as disability becomes more visible through de-institutionalisation and school integration. However, community attitudes still constitute a barrier to full participation in society. Many group members stated that negative attitudes are expressed—or interpreted—in a number of ways...staring, looking away, lack of access to mainstream services, poor employment opportunities and other discrimination, and by simply ignoring people with disabilities. In doing this, the community is interpreted as saying to people with disabilities 'you don't count'. Participants felt that, ultimately, negative attitudes work against the aspirations of people with disabilities, whether it be in terms of undertaking training, getting a job, socialising or simply having basic needs met. Many parents believe that attitudes are thought to directly impact on children's ability to participate in activities like after-school programs or holiday camps and thus limit their potential.

There are all those pre-conceptions about disability...that you can't cope with things, can't be organised, can't measure up.

[Middle-aged woman with a physical disability]

Level of family and outside support available

The potential to formulate aspirations and, in some cases, the potential to **have** a future is said by focus group participants to rest heavily on the level of family and other support available. Family can help equip a person with a disability for life; parents of children with disabilities appear to cope better when extended family is supportive. Concerns were expressed, however, that much rests on the family's ability to advocate; and while government funding is considered vital and is highly valued, there remain some large gaps. Essentially these concerns distil down to perceptions of limited funding for services such as therapy, equipment, services, in-school support, interpreters and aides, respite, training and other programs. This is complicated by often incomprehensible eligibility criteria which, according to some, leave people falling through the cracks.

Having to accept help was really hard...and when my daughter died they took it away, even though my son has Down Syndrome. Then, when he was diagnosed with autism, they gave it back. It's very unsettling.

[Parent]

Accessibility to the wider world

The world is ordered for the able and accessibility is an aspect of disability that possibly does not impinge on the consciousness of most. The reality—according to study participants—is that virtually every aspect of their daily lives is limited by access constraints. Public transport, shops, entertainment venues and restaurants, potential workplaces and schools, playgrounds and parks, streets and roads can all be inaccessible to people with disabilities.

If you can't do something or go somewhere, you automatically start thinking 'well, should I be doing this?' It affects your self-esteem because it says society doesn't give a stuff about you.

[Young woman with a physical disability]

It is relatively easy to dismiss public transport difficulties, but their effect on people with disabilities often means a very limited life—socially, creatively and work-wise. Reduced access affects self-esteem in the most basic way and casts people with disabilities as supplicants. Notwithstanding advances evident in Melbourne's most recently built sporting venues, those who have experienced the level of access offered in the United States and Canada, brought about by a combined regulatory and incentive approach, believe Victoria could learn much from the overseas experience.

Free flow of information

It appears that information in the disability sector is not filtering through adequately. Parents can often wait months or even years for a diagnosis for their child; the time of diagnosis is often a time of grieving and loss and parents feel they are ill-prepared for this. They felt that the onus was on them to access information about available services and benefits. People with disabilities also feel that information retrieval is a hit and miss affair, with many sourcing their information from friends and acquaintances rather than from more formal channels. Discussion centred on the need for a main information point; some highlighted the importance of somewhere to register their concerns and complaints; and others raised the possibility of an ombudsman for people with disabilities.

What you know already limits the extent of what you do. Once you know, it's a different story and the whole world opens up.

[Young woman with a vision impairment]

Opportunity

Equality of opportunity is a key issue for people with disabilities and there is an expectation that their opportunities will not be compromised as a result of their disability. And yet the myriad of factors impeding their life chances work against these expectations. Many barriers—artificial ones, according to study participants—stand in the way of education and employment. These relate back to the issues of access, community attitudes, information and support/resources. A very clear finding from this study is that limited access means limited opportunities.

I'd like to work more but opportunities are not freely available...I'd like to work in the area of disability, but there is not a lot of opportunity...and I need an income and those jobs are usually voluntary.

[Young man with a physical disability]

Lack of opportunity can also stem from isolation, absent or poor family relationships and inadequate resources. Those living in supported accommodation, for example, who do not have strong family support tend to miss out on the socialisation and activities that others enjoy. Limited financial resources can also result in limited opportunity, causing people to do without needed equipment or to curtail their studies due to lack of funded note-takers or interpreters.

Peer group interaction

In the normal course of things, for example at school, through services and in accommodation, people with similar types of disability often tend to be placed together. Many people find such peer group interaction 'easier' and even beneficial perhaps due to the physical and emotional growth that comes from shared experience.

Notwithstanding their individualism and desire for an 'identity', many people with disabilities indicated that they benefit from at least some regular time with others facing similar challenges. At the same time, however, they stress the need for a balance of peer and other interaction in their daily lives.

People's comprehension of what you need is very difficult...that's why amongst your own it's a lot easier.

[Middle aged woman with a vision impairment]

Health status

Health status has a direct impact on aspirations for the future. While many people with disabilities enjoy stable health, the reality for many others is often a series of health crises or, at best, a variable level of health. Conditions requiring frequent treatment or hospitalisation, or bouts of ill health, lessen participation in everyday life. How can one undertake a course of study, a job or a trip overseas, for example, when there is a strong likelihood that illness will occur?

Costs

It has been pointed out that the experience of disability often has a parallel path that leads to poverty. This was confirmed in the current study. The 'ordinary' family is simply not faced with the same kinds of expenses as one which has an adult or a child with a disability—special equipment, modifications to housing and cars, extra therapies, aids and aides, special feeding supplements and vitamins, transport and so on. Coupled with a reduced earning capacity, for example when it is necessary for one parent to give up work or when it is impossible to get a job, the financial outlook is often bleak.

Your independence depends on the money you have got.

[Young man with a physical disability]

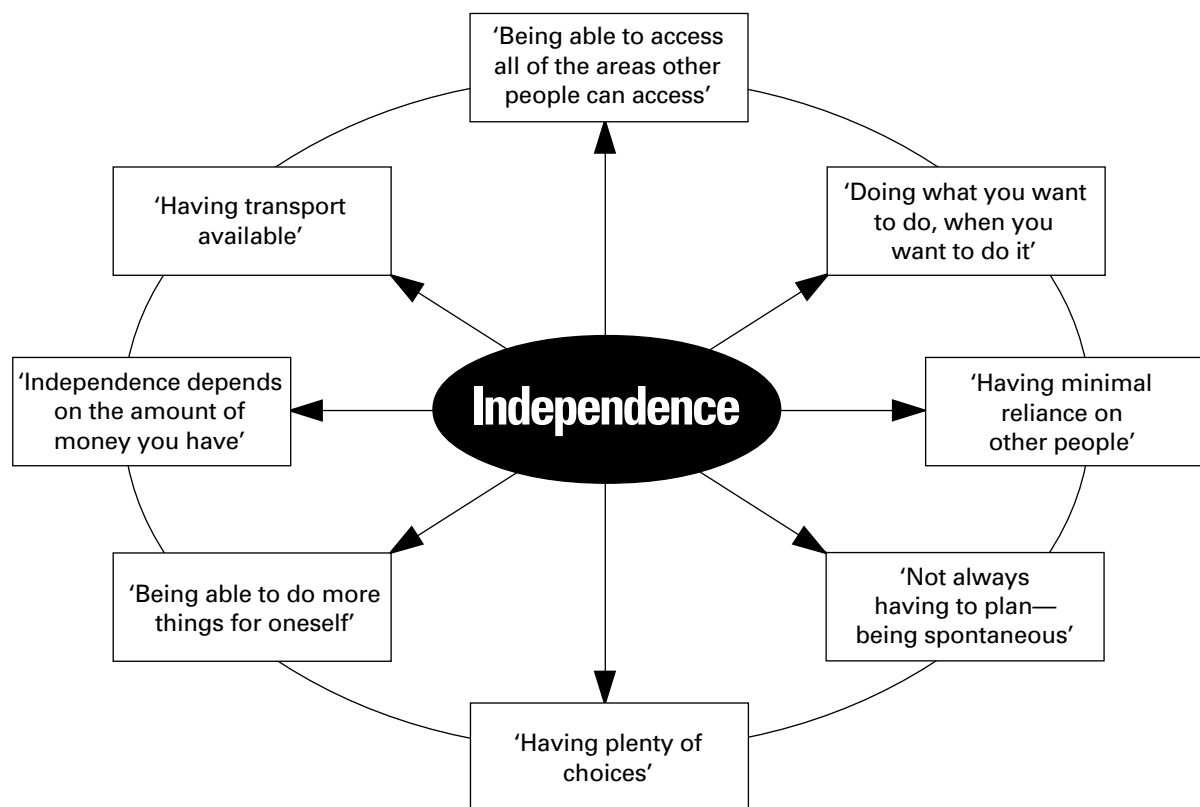
Discussion also centred on the high cost of socialising—the need to purchase two tickets to a concert or other entertainment event (one for the person with a disability and one for the carer), and the fact that while maxi-taxis are half-price they are still a relatively costly form of transport. The net effect of the high costs associated with having a disability is said to be a limitation on the potential to achieve one's aspirations and, in particular, the striving for independence.

Quality of Life

In the general community the parameters attached to quality of life could include material wellbeing, good health, happy relationships, employment, family and so on. For people with disabilities, if quality of life were to be boiled down to one word, it would be 'independence'. Independence is probably the aspect of life that most people tend to take for granted. For people with disabilities, however, independence is something that they must strive for every day of their lives. Independence is essentially freedom—the freedoms that are seen to be enjoyed by people who do not have disabilities. As one study participant commented, living with a disability is an 'everyday struggle for independence in a normal world'.

Interpretations of what constitutes independence, according to study participants, are outlined below.

Figure4: What Constitutes Independence?



A positive outlook, making the most of every day, is another integral life quality ingredient. An enhanced quality of life is also said to relate to acceptance of one's self including one's disability. While this may be seen to be the opposite side of the coin to independence, the ability to maintain self-esteem is seen as integral to a fulfilled and happy life. Acceptance of one's self appears more difficult among those who developed a disability later in

life, compared to a disability existing from birth or with an early onset. Underlying much of what is said about disability and quality of life are the concepts of identity and self-esteem. People with a disability strive to maintain their identity as a person first, not to wear a label that says 'disability'. Identity and self-esteem also relate to family and acceptance in the community, as well as ability to participate in community life.

To have quality of life you need to be happy with yourself, to have a high self-esteem, an identity. Not be depressed.

[Young woman with a hearing impairment]

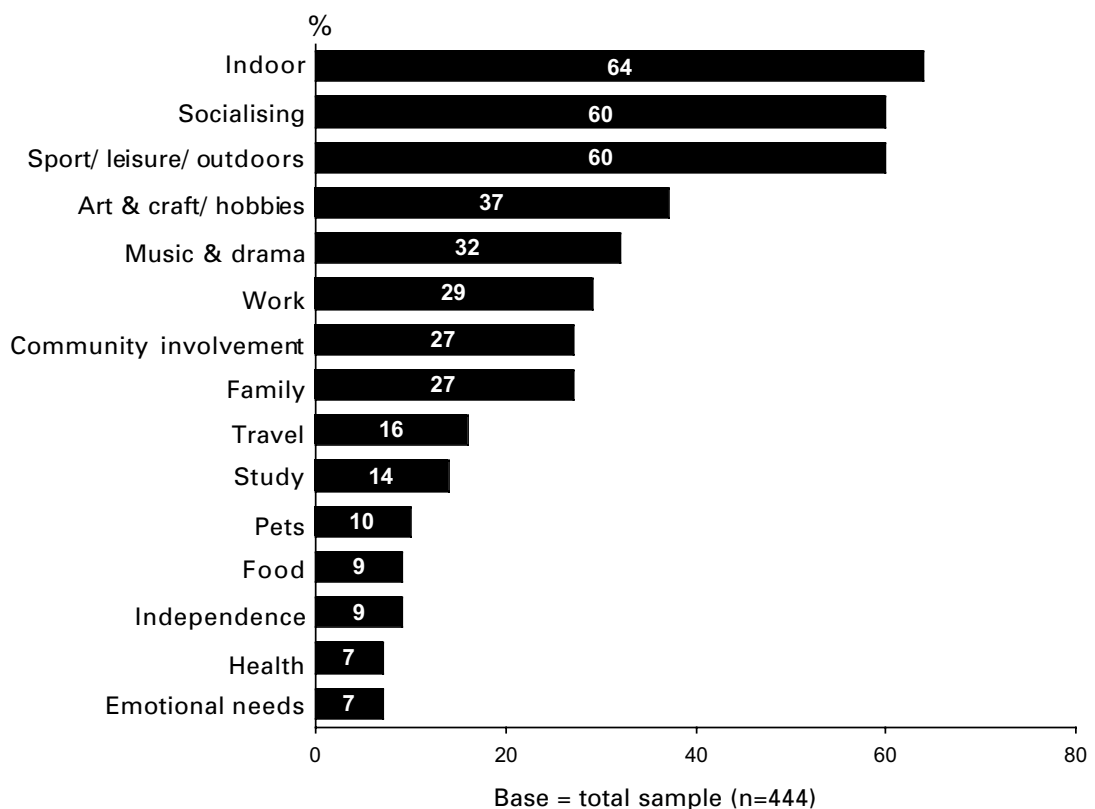
Underlying discussions it is also clear that stability—as it relates to continuity of care or carer funding, a home, ability to plan ahead, health, availability of respite, an income—underpins quality of life.

Current Activities

Activities can be at once recreational and developmental, providing opportunities for communication, social development and the acquisition of skills. Activities are also important in forming goals and aspirations for the future. Respondents in the face-to-face interviews were first asked to talk about the activities they currently enjoyed participating in and then to move on to the more challenging area of aspirations.

In learning about the current activities of people with disabilities participating in this study, we found that these spanned the gamut of those occurring in the wider community. In particular, people with disabilities value both indoor activities as well as those that take them out into the community. Almost 50 different activities were mentioned. These activities have been grouped into various categories and how often they were mentioned (frequency) is contained in figure 4 below.

Figure 5: Net Activities Enjoyed—Total Sample

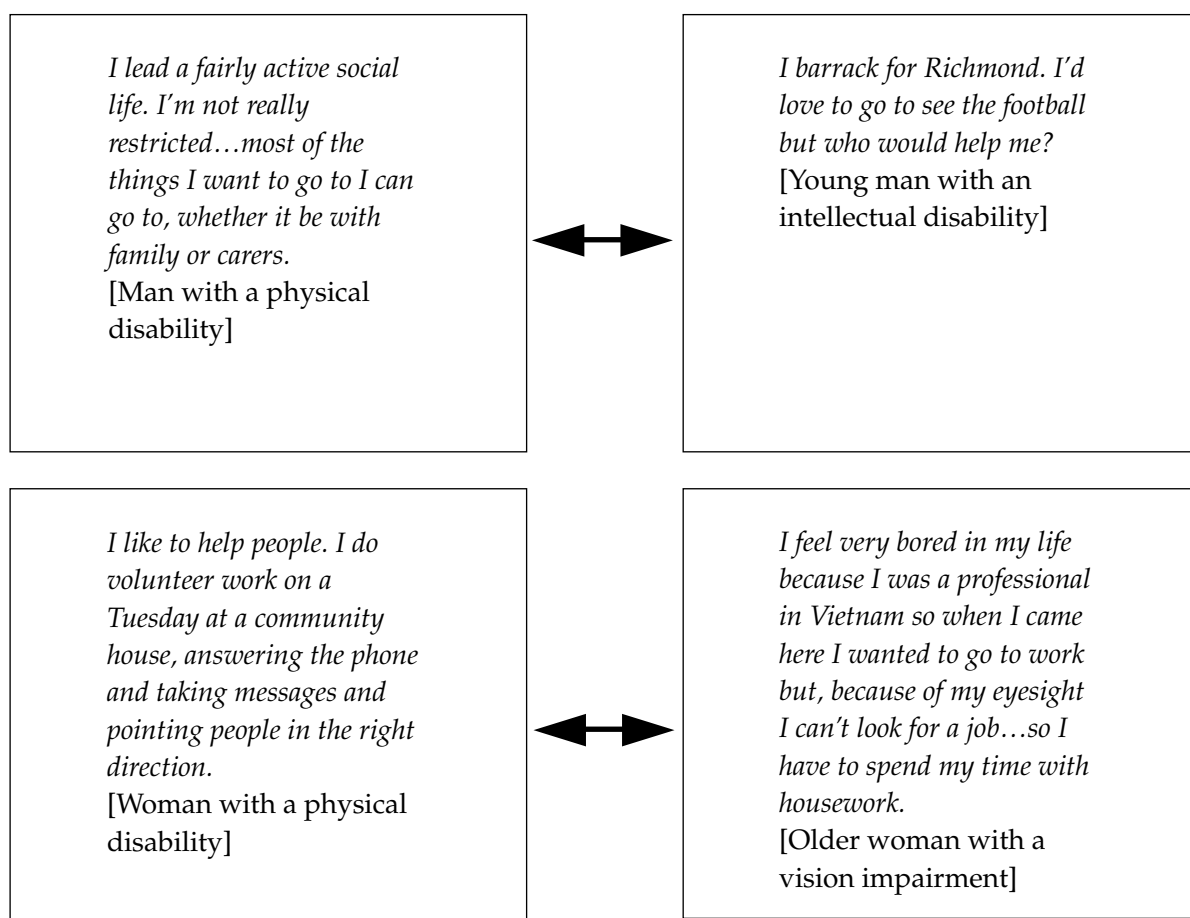


Reasons for enjoying these activities are wide-ranging, although some key rationales are repeated. Indoor activities are relaxing or calming, they give a sense of accomplishment, provide an escape from day-to-day life and the opportunity to be independent. Importantly, many people find when undertaking indoor activities that they are not bound by their disability. People stated that the benefits of socialising included a change of scene, feeling good, independence and self-esteem. The attraction of sporting and

other outdoor activities lies in the physical exercise they provide, just being out in the sun, relaxation, meeting people, freedom and independence; as one young man said: 'I love being out in the sun and will go as far as my wheelchair will take me'.

Around three in 10 people cite work as an enjoyable activity. While work provides social interaction it also promotes a sense of achievement, responsibility and participation and, importantly for many, it also provides an income.

The barriers to more frequent participation in chosen activities are both personal and external. It seems that the more a person participates, the less likely he or she is to see barriers. Often, participation has less to do with level of support needed than it does with level of available support as indicated by the following comments from people with high support needs...



The most commonly mentioned external barriers to participation in favoured activities are:

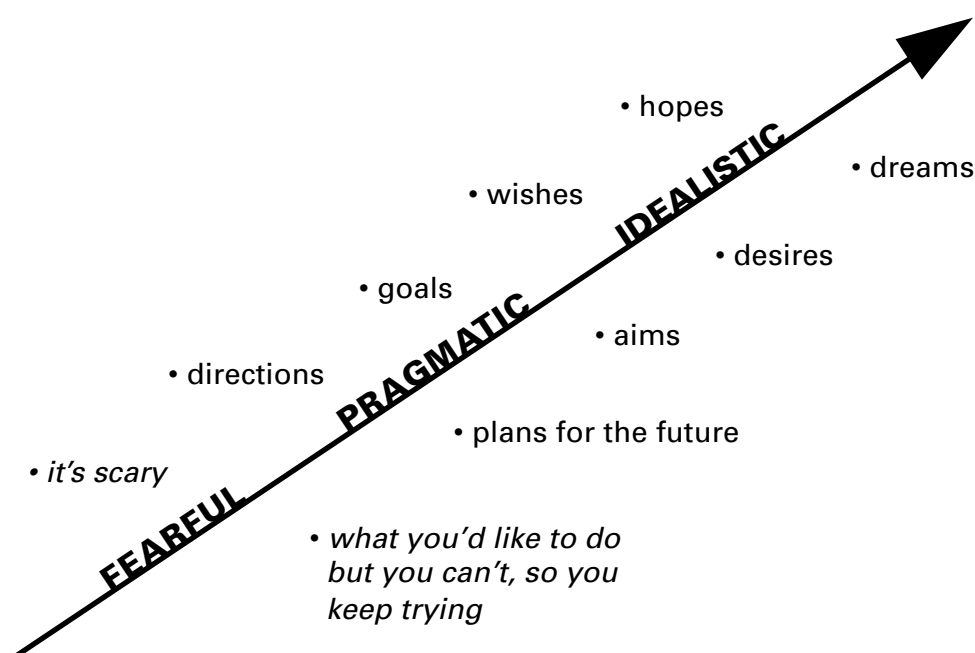
- **Negative attitudes in the community.**
- **Insufficient services or funding**— support services; funding for the activity, transport, and/or equipment or materials.
- **High cost, limited income.**
- **Access issues**—steps, buses, light switches, disabled toilets, footpaths, kerbs, seating.
- **Lack of, or difficult to access, information.**

Aspirations

Definition and Importance

The term 'aspirations' throws out a challenge about what the future holds and, often, the initial reaction is to recoil from this challenge. It evokes an assortment of emotions and interpretations that range from the pragmatic to the more tenuous.

Figure 6: Definitions of Aspirations



People with disabilities who confront the uncertainties of health status, accommodation, eligibility for extra therapies and programs and so on, map out a future that is far from stable. Parents of children with disabilities, in particular, can find the future too uncertain to contemplate. A child who can be relatively healthy one day, can be profoundly ill the next; sometimes additional disorders are diagnosed. Often parents are unsure about issues such as schooling, eligibility for assistance, work and future accommodation, all of which are counter to future planning. So, thinking about future aspirations invites thoughts about all of these doubts in their lives.

It's too scary. You don't want to go there, basically.
[Parent]

Another major factor impinging on aspirations is society at large. Living in a society which is often seen to be inaccessible, exclusive and unaccepting of people with disabilities can have the effect of lowering aspirations and expectations.

This study found that the more secure people feel in terms of control over their life, the more concretely they interpret 'aspirations'. The less confident tend to use words like 'wishes' or 'hopes' when discussing aspirations, the more confident refer to 'goals', 'aims' and 'directions'.

Notwithstanding these attitudes, however, all people agree that it is vital to have aspirations—without them life would have no meaning.

What Are Aspirations?

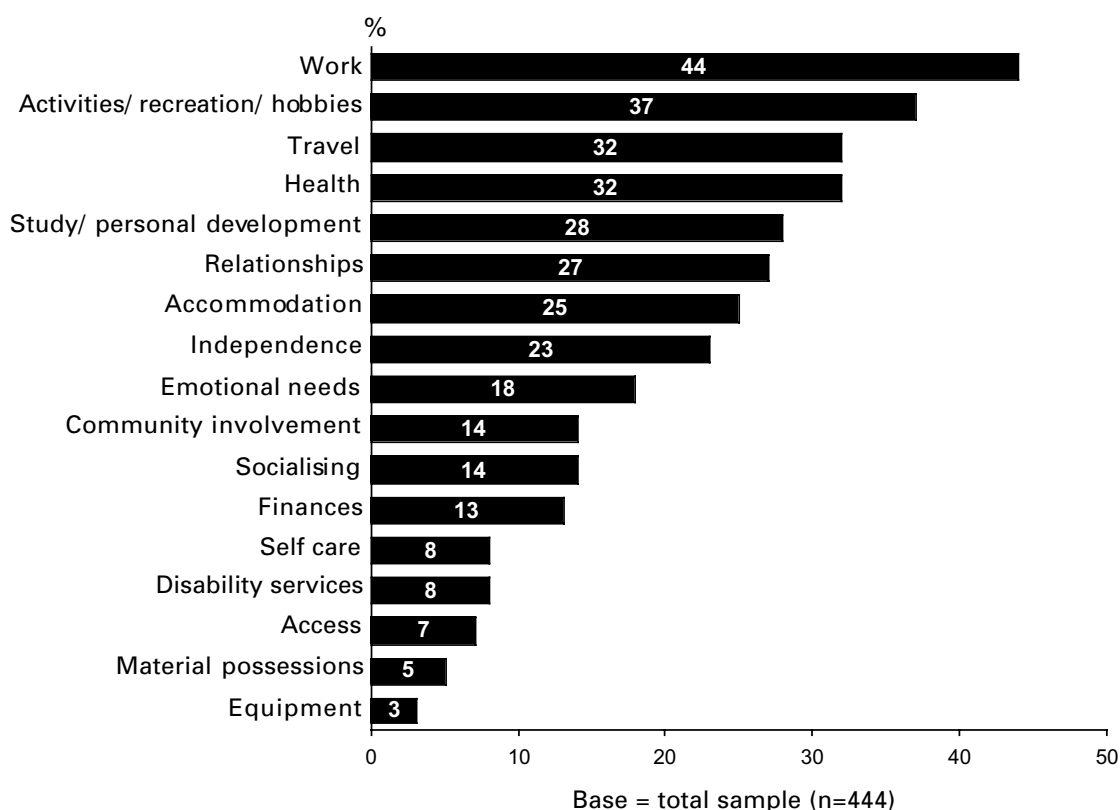
As could be expected in the wider community, the aspirations of people with disabilities span from being able to go to the movies more often to becoming a veterinary surgeon. For some, the horizons are wide, whether due to their own personal outlook or to the supports and plans that are in place for them. For others, barriers and limitations exist to such a degree that, at worst, they have difficulty thinking about next week let alone next year or a few years hence. Sometimes people in such difficult circumstances reached a point where, they said, what was missing was the courage and confidence to plan ahead. It is no understatement that the future for people with disabilities is often about small steps and big leaps of faith. Take, for example, the following comment:

Well, first I'd like to be alive. I'm studying writing at the moment, I'd like to have the opportunity to get something published...

[Young man with a neurological/physical disability]

Overall, more than 50 different goals or aspirations were mentioned, with the most frequent three relating to work, recreation and travel. As with the activities enjoyed, aspirations were grouped together, under themes or categories, by frequency (see figure 7).

Figure 7: Net Goals and Aspirations—Total Sample



Forty-four per cent aspire to **work**, whether this is to get a job, improve one’s job, move from a voluntary to a paid job, establish one’s own business or retain a current job. The potential to have a rewarding job (or simply a job) is very important right across the types of disability and levels of support need. Those working in supported employment expressed strong satisfaction with their jobs, which can often fit with their own personal interests, for example, art, woodwork or gardening. Many people with physical or sensory disabilities spend part of their week working in a voluntary capacity. While this kind of work brings personal satisfaction, there are many who would prefer the status, fulfilment and the income associated with a professional career.

The vast majority who express an aspiration relating to work (90 per cent) have taken some steps towards this aim. These include acquiring work skills through training or work experience, returning to study, networking and sending off job applications, and continuing involvement with current programs, voluntary work or support groups until an opportunity arises. While around one in seven are unaware of any barriers to their goal, among the remainder there are fears that lack of opportunity or choice, high competition, community and employer attitudes, lack of finances or training and the disability itself, may impede them. Some see their own lack of self-esteem or poor health as a significant barrier to work.

It’s hard enough for anyone to get a job these days. You have to have such an edge, so what chance do I have?
 [Younger woman with a vision impairment]

I want to be an integration aide, I have done two classes now...but whether I would be able to do it. I have to learn not to say as much in the interview about my disability.

[Young woman with a physical disability]

The second most frequently mentioned type of aspirations centred on **activities, recreation and hobbies**. As seen earlier, recreational activities are strongly linked to the benefits of social interaction, enhanced self-esteem, improved health and independence. Around 80 per cent of those who have this aspiration report having taken some steps towards it. The most important steps are participating in group activities, talking to carers/staff, maintaining current activities and programs and developing individual plans. While there are those who rely on their own self-determination, some depend on family, friends and support staff for encouragement. However, around 75 per cent foresee one or more barriers in the pursuit of such activities. The need for assistance/dependency and poor personal finances are two major hurdles; the disability itself, low self-esteem, health concerns, behavioural problems and poor concentration are also likely to get in the way. The perceived external barriers to participation in recreational activities include staff shortages, the need for better staff training, transport difficulties, distance and inadequate disabled access.

I don't do as much as I would like to...I've noticed in the last six months the prices keep going up...and if I take a carer it costs double.

[Man with a physical disability]

Around one-third of those interviewed aspire to **travel** in the future and eight in 10 have taken some steps in this regard, albeit tentative ones. 'Thinking about it', making enquiries, relying on someone else to make plans and saving are the main moves made.

While many are eager to travel, 95 per cent can see some potential barriers. The main one is lack of money, but the need for assistance or dependency also looms large. Others are concerned about the disability or ill health getting in the way. Another hurdle is the perception that there may be inadequate disabled access when travelling.

I'd like to go to Europe if my eyesight stays the way it is...but if it gets any worse that will stop me from going.'

[Young woman with a vision impairment]

I've always had trouble with my sight but I haven't let it interfere with my life. There's a lot of things I would like to do in the future, like climbing Uluru.

[Older woman with a vision impairment]

A similar proportion—around a third—have aspirations that centre on **health**: a cure, a medical breakthrough, improved health or diet, enhanced physical activity, improved mobility and traditional and alternative therapies. To this end, a wide range of steps has been taken. Some of the main ones are hydrotherapy programs, exercise and sport, watching one's diet and general health, seeking treatment or medication, traditional and 'new' therapies and encouragement from family, friends or carer. There are, however, many perceived obstacles. Concerns about health and wellbeing

and the physical limitations of the disability are the main ones. Another large hurdle working against the health aspiration is limited personal finances in conjunction with high costs. Staff shortages, low self-esteem, community attitudes and emotional issues are other potential barriers to the achievement of health aspirations.

Study and personal development are among the aspirations of 28 per cent of the sample. This theme encompasses completing school, enrolling in a degree or TAFE course, developing academic/literacy skills to full potential, learning to communicate and undertaking work-related skills training. The vast majority of this group—more than 90 per cent—are already well along this path. Making enquiries, continuing with studies, undertaking therapy and having the assistance of someone else are the main avenues being pursued. In addition, some are learning disability-specific communications techniques or using Braille or sign language interpreters while studying. There are barriers, however, according to 90 per cent of people with this aim. Lack of personal finances combined with high costs is the single biggest hurdle to undertaking study or personal development. Next is the disability itself or the need for assistance, low self-esteem and limited concentration or illiteracy. Progress will also hinge on other people and special facilities, as well as government funding for services and staff.

I just want a relationship. I can meet them, I just can't keep them.
[Young woman with a physical disability]

Just over one-quarter of those interviewed express the desire for a **relationship**. This means either greater or continued involvement with the family or having a family of their own. To some it's about friends and to others it relates to a close meaningful, sexual relationship. In working toward this goal people talk about all the social aspects of life—family contact, outings, phone conversations, communication, youth groups and social clubs, interaction with others and meeting people on the Net.

Eight in 10, however, can see potential barriers and the main one seems to be finding someone who would be accepting of the disability. Lack of finances, too, is a large hurdle. Then there is the disability itself, the lack of motivation, low self-esteem, the need for assistance, emotional barriers and poor public perceptions of people with a disability, according to those with this goal.

I wouldn't mind getting married but I couldn't put up with not being accepted.
[Young man with a physical disability]

In the focus group discussions a very common theme was that of future **accommodation** options; 25 per cent of people mentioned this aspiration in the face-to-face interviews. Most have taken some steps in this regard, either by making enquiries about or moving to improved living arrangements or a Community Residential Unit (CRU).

We've been at Kew a long time and would like to be in a house. We'll be able to do more things, but we'll still need more programs to go to.
[Middle-aged woman with an intellectual and visual disability]

I'd like to be able to live independently, perhaps share a flat with someone. My thing is not having the guts to do it. Fear of the unknown, I suppose.
[Young man with a physical disability]

Others have looked at modifying or extending the home. Some are relying on others to make plans, some have their name down on a waiting list, some are saving up. Family encouragement and learning daily living skills are other steps along the way. Again, however, there are some potential obstacles. The need for assistance, lack of finances, long waiting lists and lack of funding for suitable housing are all possible barriers. Many parents are fearful that little forward planning is undertaken for supported accommodation needs and that people of very different ages and with very different levels of support needs are inappropriately placed together as places become available. Ultimately, some see this aspiration as being limited in terms of both options and community attitudes.

Independence is the other major aspiration of people with disabilities, being cited by more than 20 per cent of the sample. A very high 95 per cent of this group see some barriers to the achievement of independence, the main ones being the physical or mental limitations of the disability and limited finances. Again, however, we find that attitudes—whether they are one's own, that of governments or the community at large—could potentially restrict the achievement of independence.

Other goals and aspirations, outlined in figure 7, relate to **emotional needs** (including happiness, respect, a meaningful existence, improved quality of life and a safe environment), **community involvement, socialising, finances, self-care** (for example maintain and/or improve daily self-care), **disability services** (including access to information about my community, having an in-home carer, enhanced access to disability services), **access** (physical access to buildings and public transport, increased availability of accessible transport), **material possessions and equipment** (for example, wheelchair, scooter, guide dog, electronic communication, Internet).

There are some common themes coming through in relation to all of these aspirations. If there is going to be a limitation, then more often than not this will be related to one or a combination of the following barriers, which are listed in order of the weight given to them by study participants:

- Ability related—physical, intellectual or behavioural limitations, dependence.
- Government policy and services—policy, concerns regarding bureaucracy, limited funding, staff shortages or quality, potential loss of programs, accommodation shortages.
- Limited personal finances, high costs, need to budget.
- Health and medical issues—physical wellbeing, safety concerns.
- Personal, attitudinal and emotional issues—confidence, self-esteem, anxiety.
- Access and transport—access to transport, geographic location, insufficient disabled access in shops, workplaces and so on.
- Community attitudes—public and employer perceptions of people with disabilities.

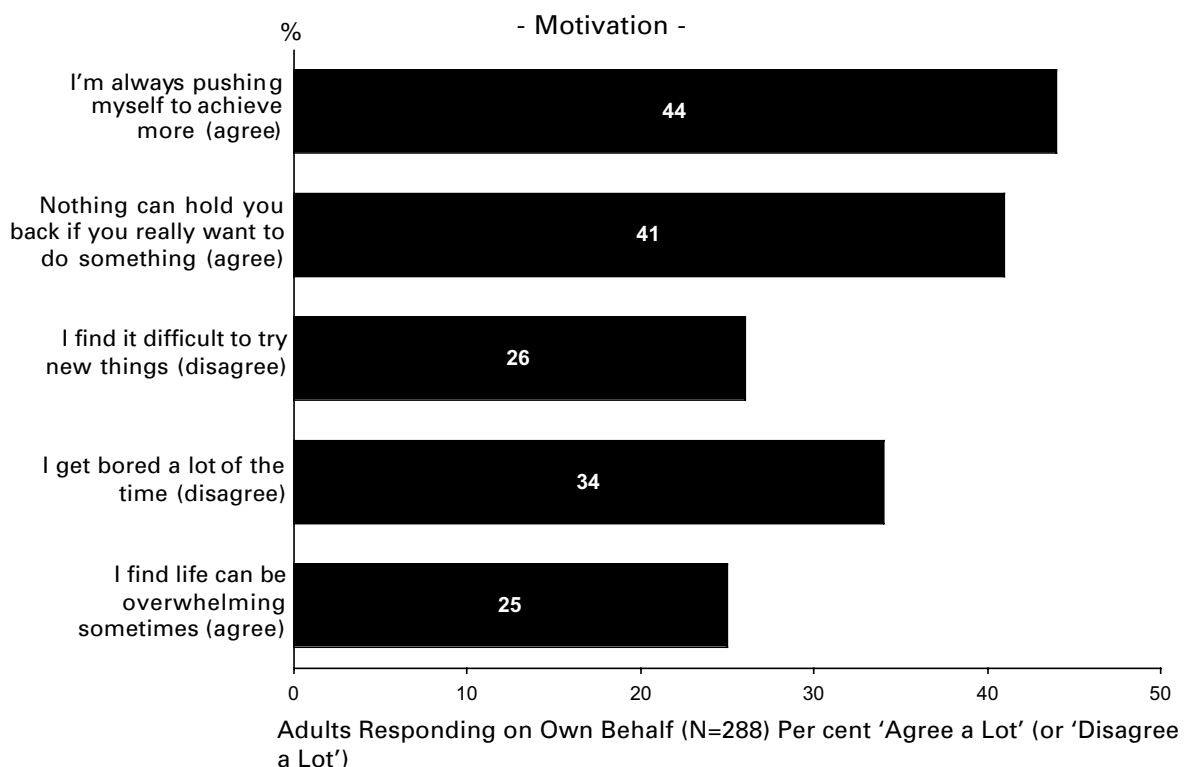
- Other commitments—to work, study, family—or the need to make a commitment.
- Decision in someone else’s hands—doctor, carer, teacher.
- Lack of information—poor communication.
- Lack of opportunity.
- Family concerns.

Attitudes toward Disability

In attempting to further understand how aspirations and, in particular, perceived barriers to these are formed, it is also important to understand the attitudes of people with disabilities towards the experience of disability. The attitudes of adults with disabilities (who responded on their own behalf) in terms of their agreement or disagreement with a series of statements relating to disability are presented below.

The first series of statements relate to **motivation**. Two very strong attitudes are evident here: 'I'm always pushing myself to achieve more' and 'nothing can hold you back if you really want to do something'. More than four in 10 people express strong agreement with these statements. People with disabilities are more likely to disagree than to agree with the statements: 'I find it difficult to try new things' or 'I get bored a lot of the time' (although note that around 17 per cent agree 'a lot' with these statements). The majority, however, agree (25 per cent 'a lot', 29 per cent 'a little') that 'life can be overwhelming sometimes'.

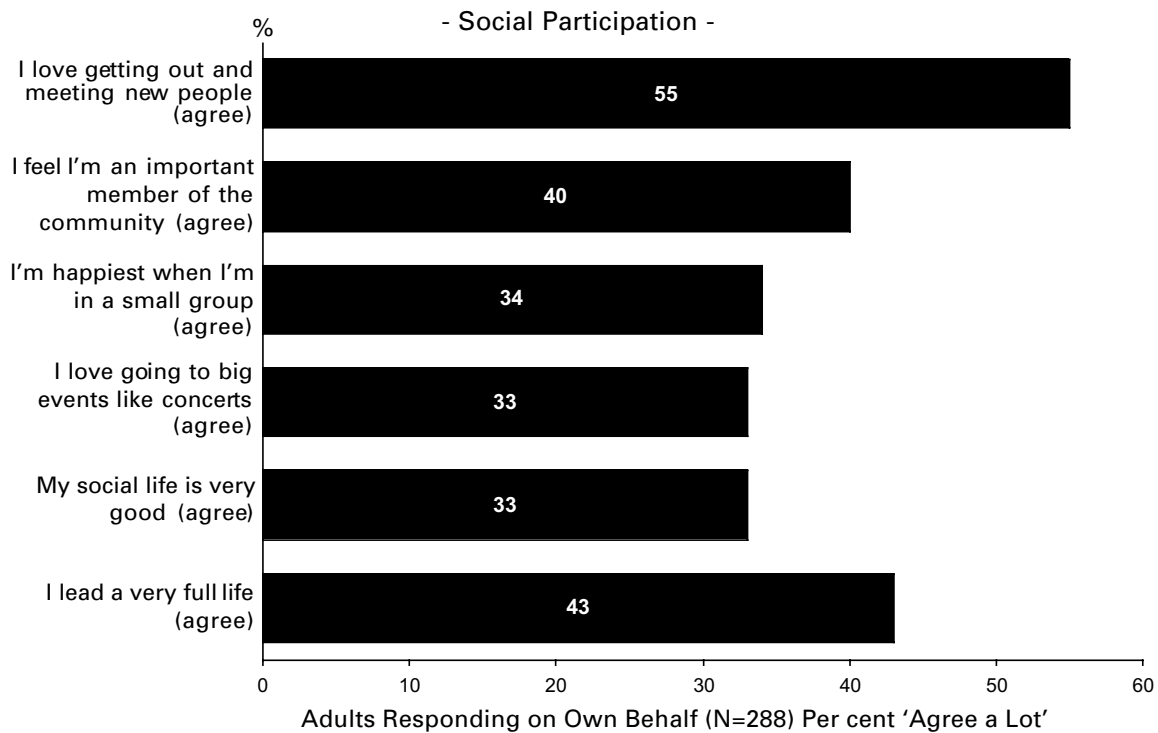
Figure 8: Attitudes to Disability—Motivation



Next, attitudes to **social participation** are explored. The strongest finding here, confirming previously discussed results, is agreement that: 'I love getting out and meeting new people' (55 per cent agree 'a lot'). And, for one-third, this goal is fulfilled: they agree 'a lot' that: 'my social life is very good'. Forty-three per cent agree 'a lot' with the statement 'I lead a very full life'.

Some people are happier socialising in small groups, others prefer big events. Finally, four in 10 people with disabilities strongly agree: 'I feel I'm an important member of the community'.

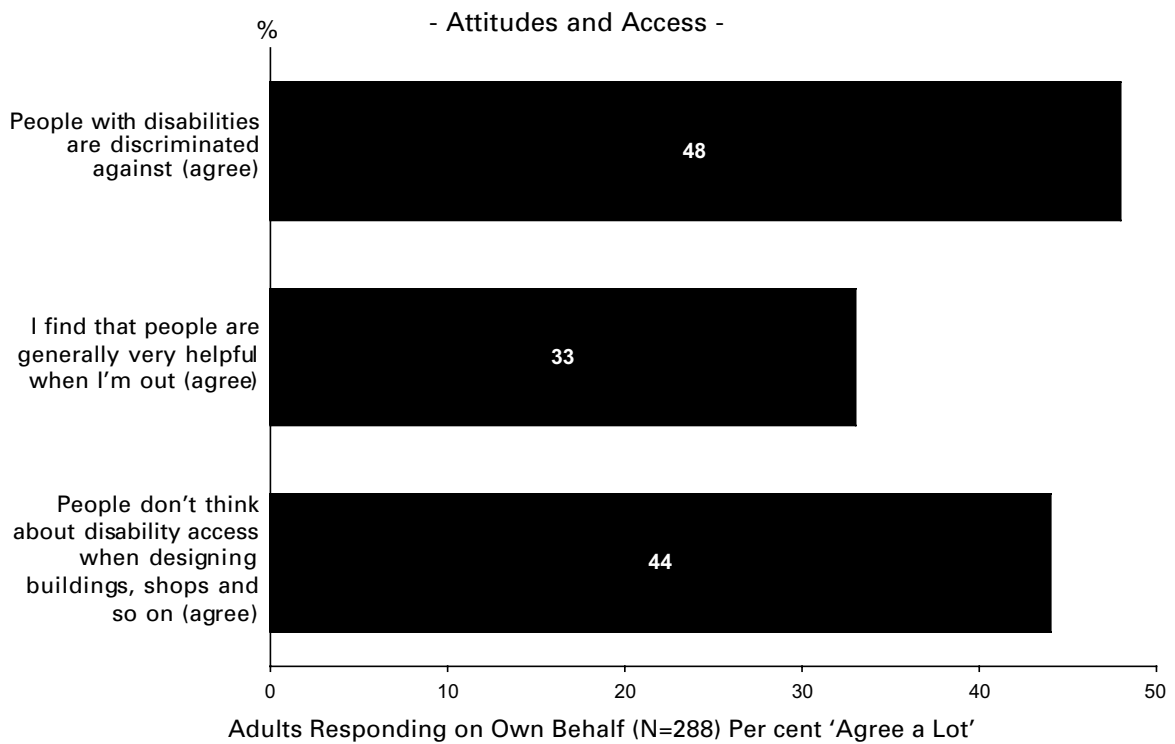
Figure 9 Attitudes to Disability—Social Participation



A key finding in relation to **attitudes and access** is the 48 per cent strong support for the statement: 'people with disabilities are discriminated against'. Forty-four per cent believe: 'people don't think about disability access when designing buildings, shops and so on'.

Notwithstanding these attitudes, one-third agrees 'a lot' that: 'people are generally very helpful when I'm out'.

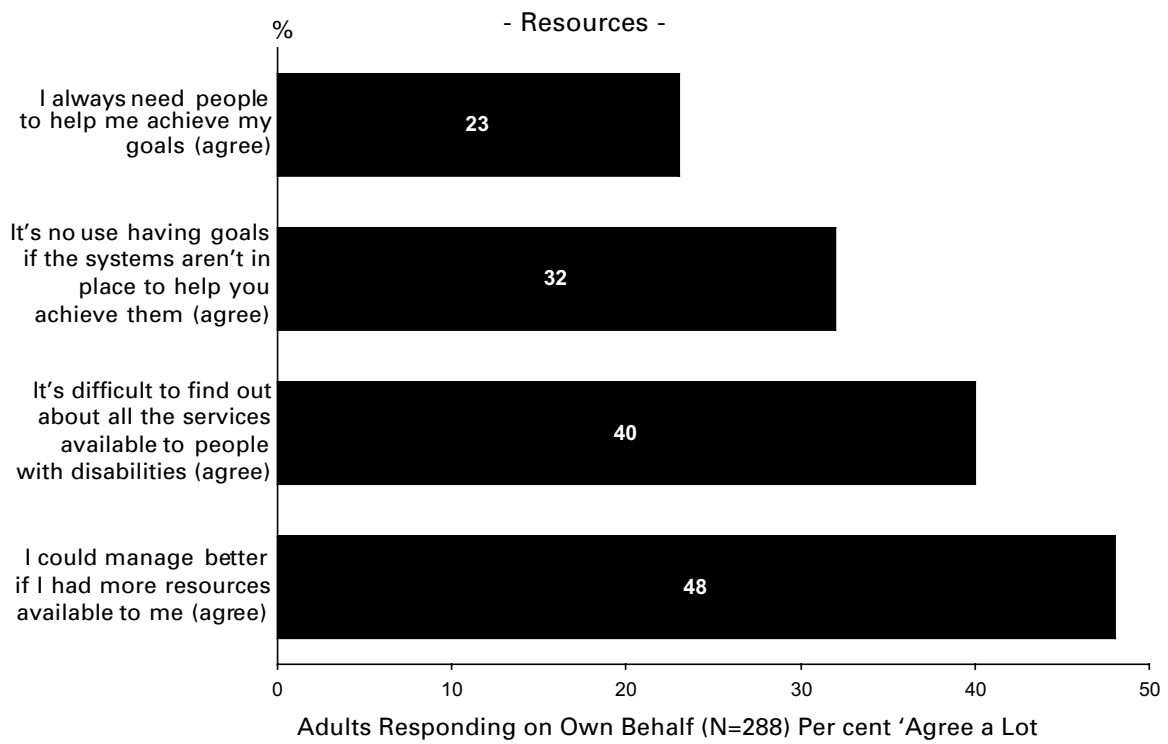
Figure 10: Attitudes to Disability—Attitudes and Access



One of the main findings of this study is the dependency of people with disabilities on **resources**, both physical and financial. In relation to resources, just on one in two people agree 'a lot' that: 'I could manage better if I had more resources available to me'. While almost a quarter agree: 'I always need people to help me achieve my goals', one-third also agree 'a lot': 'it's no use having goals if the systems aren't in place to help you achieve them'.

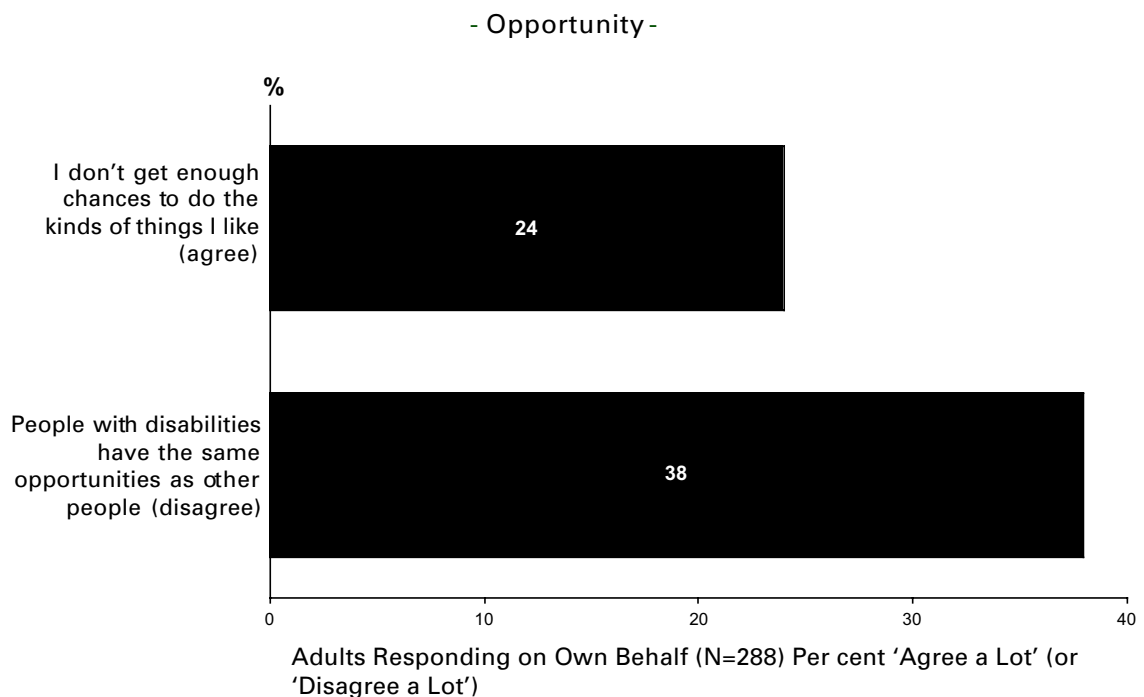
In confirmation of the focus group findings, four in 10 agree 'a lot' that: 'it's difficult to find out about all the services available to people with disabilities'.

Figure 11 Attitudes to Disability—Resources



Equality of **opportunity** is an inherent right of people with disabilities. However, 38 per cent disagree 'a lot' that: 'people with disabilities have the same opportunities as other people' and 24 per cent agree 'a lot' that: 'I don't get enough chances to do the kinds of things I like'.

Figure 12: Attitudes to Disability—Opportunity



Conclusion and Challenges

The aspirations of people with a disability mirror those of all people, fundamentally confirming the need for an inclusive view of our society. Those people with disabilities who participated in this study were very candid in expressing their views. They are mindful of the many changes that have taken place within the 'disability sector' over the past 15 to 20 years and the moves made toward integration. They acknowledge the wide range of support services and initiatives that have been put in place. And yet, they still feel marginalised in many aspects of their lives. Quality of life, to them, centres on independence—the independence to pursue their goals and aspirations. Their disability is confounded by the seemingly artificial limitations that surround attempts to participate fully in our society.

As with others, the lessons that are learned in the day-to-day lives of people with disabilities provide the grounding for their future plans. This study revealed that those who participate most fully also appear to have a broader outlook and greater expectations for the future. Thus, a limitation placed on participation may well result in diminished aspirations.

In general, the interests of people with disabilities mirror those of the rest of the population. They variously enjoy sport, outings, creating things, indoor hobbies, home-making, playing games, computers, music, the outdoors, studying and working and a plethora of other activities.

Evaluation of the key activities currently enjoyed by people participating in the study and their future aspirations reveals that, in the main, these are motivated by the drive to participate in mainstream community life. One of the major aspirations of people with disabilities revealed in this study relates to work: to get a job, improve one's job, train for a job and so on. The benefits of working, according to study participants, are a sense of achievement, responsibility and, in many cases, earning an income. But often, the major advantage of working is that it can place people with disabilities in the centre of the 'action' rather than on the periphery. A similar attitude underlies the interest expressed in socialising. People with disabilities want to go out and experience the world rather than be trapped at home for much of the time. But again they often find they are excluded.

A key question the study asks is about how often people are undertaking their preferred or favoured activities and whether they are satisfied with this. The response is very often in the negative. In addition to the constraints of the disability, an amalgam of 'external' factors serves to limit participation. Likewise, when discussing future aspirations, potential barriers to their achievement are raised.

These barriers or potential barriers clearly centre on the following factors:

- **Attitudes:** a limiting factor according to many people with disabilities is the negativity of attitudes at the general community level. There is a sense that people do not understand disability or they fear it and thus

tend to shun or ignore people with disabilities. Those people who have a highly visible or, alternately, a hidden disability, appear to suffer most. Negative attitudes reinforce feelings of low self-esteem.

- **Access:** it is probably necessary to 'walk a mile in their shoes' to understand the widespread difficulties experienced with access. The provision of infrastructure in Victoria is considered by participants in this study to overlook the needs of people with disabilities. Put simply, shops, transport, entertainment venues, restaurants and even parks are often unable to be accessed by people who use wheelchairs, people who are sight or hearing impaired and people with other types of disability.
- **Financial:** the association between disability and limited financial resources is a very real one. Being unable to work or, at best, able to earn a limited income only and, at the same time, being confronted with the 'extraordinary' costs of having a disability is a combination that ensures many activities or goals are simply unaffordable. Poor finances mean limited opportunities.
- **Resources and services:** while there are perceived to be many excellent resources and services provided through Government funded and other programs, many of these are thought to be 'stretched' and thus often fail to meet needs. Lack of or limited resources is very often the restricting element in people reaching their full potential, particularly in regard to education.

Living, and progressing, with a disability requires courage and confidence. It often takes small steps and big leaps of faith to embark on an activity that is beyond the 'safety zone' of home. It is incumbent on all of us to support people in these endeavours to the fullest extent. The challenges that arise from this study are simple and centre on the need for inclusiveness, access, positive attitudes, resources and information.