The Social Construction of the Disability: Social Inequality in Hong Kong

by

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Tam Tat-sing
15th September 2004

Abstract of thesis titled 'The Social Construction of the Disability: Social Inequality in Hong Kong' submitted by Tam Tat-sing for the degree of Master of Philosophy at the Hong Kong Polytechnic University in November 2002.

The objectives of this study are to examine how disability is socially constructed in Hong Kong and to explore the extent to which people with impairments are able to resist social restrictions upon their living. By following the materialist social model of disability, we focused on the prevailing forms and patterns of social restrictions upon the people with impairments and tried to see how disability is created. Data are mainly collected from in-depth interviews. Twenty people, who are wheelchair-users but with different kinds of impairments, were interviewed within the period from September 2001 to August 2002.

I divide our analysis into three parts. The first part is about the social restrictions that are constituted through spatial arrangement, the form of provision of social services and medical practices have been examined. It was found that disability was created because of people's concern with risk. The related parties, like security guards, policemen and family members of the people with impairments, restricted the scope of geographical mobility of the people with impairments because of their concerns for the safety of the impaired people and themselves. Their subjective interpretations of risk prevented them from offering assistance to the impaired people and therefore people with impairment were thus 'disabled'.

Based on the examination of the social restrictions upon impairments, I turned to study the psycho-emotional dimensions of disability. We found that owing to their experiences of disability, people with impairments felt anxious, dismayed and frustrated. Disability, understood as the outcome of social restrictions upon impairments – the sense of *doing*, affected the sense of *being* of the people with impairments. However, we found that people with impairments reacted against social restrictions with their own strategies and knowledge. In reaction to the dominance of bio-medical knowledge, people with impairments, on the basis of their personal experience and knowledge, formulated their own ways of living.

Informed by the materialist social modellists like Carol Thomas, we further examined the significance of impairments to the personal life of people with impairments. Contrary to the social model of disability, which suggests the idea that impairments are not essential in the study of disability, we found that impairment effect is of great significance. Impairments also affected the psycho-emotional state

of people with disability. Despite of this, when people with impairments found medical practitioners helpless, they were able to empower themselves through the formation of optimistic world outlook and practicing their own ways of healing. In this respect, we discovered covert struggles between the impaired people and the professionals. In short, with the concept of psycho-emotional dimensions of disability, we examined the lived and embodied experiences of the impaired and pinpointed the aspects of what people with impairments are doing and the aspects of how they act/react in facing disabling restrictions. Moreover, facing the bio-medical dominance, the interviewees of this study made use of their embodied and lived experiences to counter this imposition. It shows that people with impairments act as an active person against social construction of disability rather than being a passive victim.

This is the first study in Hong Kong showing the impacts of disability and impairments on the psycho-emotional dimensions on the people with impairments. However, we were only concerned with one form of impairments (i.e. wheelchair users). More research is needed to examine the link between other forms of impairments and the rise of disability.

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Chapter 1

Introduction

Research Objectives

The first aim of this study is to examine how social inequality, which is measured in terms of spatial, temporal and social dimensions, is socially constructed against impaired people in Hong Kong. The focus is not only on the effectiveness of protection to the rights of people with impairments but also the ways of construction of social inequality by professional and laymen practices. The second aim is to explore the extent to which risk management shapes and constructs of disability in Hong Kong society. We shall pay specific attention to the interactive relations between social practices and risk management in the process of social construction of disability that leads to imposition of restrictions on the activities of disabled people in the end. These two aims are highly related to the current situation in which people with impairments have encountered in Hong Kong. The third aim is to examine the psycho-emotional dimensions of disability and impairments prevailing among people with impairments. It is this aspect of disability that a feminist disability researcher Carol Thomas has emphasized. This comes up with our fourth aim that is empirically applying the concepts psycho-emotional dimensions of disability to the study of disability in Hong Kong. The last but not the least aim is to find out whether the people with impairments, in face of socially imposed restrictions, are totally passive, or are able to resist against the dominance of bio-medical practices and the social discriminatory practices in their daily life.

To realize these objectives, the questions are posed as follows:

1. to examine how social barriers against accessibility for disabled people to places are socially constructed in Hong Kong;

2. to explore whether the major determinant factors, namely the risk management and risk perception, constitute the process of social construction of disability;

3. to examine the impacts of disability on people with impairments, with particular concern for the psycho-emotional dimension of disability and impairments; and

4. to understand the extent to which people with impairments are able to resist against the dominant social practices that would effect disability.

The current situations of disability in Hong Kong

It is necessary to present a brief account of the current social situations about disability in Hong Kong in order to contextualize our discussion. At present, there are three kinds of institutions operating to deal with the issues arising from disability, namely legislation, social policy and social services. Legislative institutions have not been able to entirely eliminated social inequality between the impaired and the non-disabled. The Disability Discrimination Ordinance was put into effect in 1995 followed by the establishment of the Equal Opportunities Commission (EOC) Bureau. The two major tasks of the Bureau are to handle complaints and advocate anti-discrimination practices through civic education. At the end of March 1997, the EOC 1996-97 report revealed that the EOC received nineteen complaints. However, these figures tell us nothing about the degree of the inequality situation of the impaired people, or about the reasons for the growing inequality that the impaired have suffered. I found that the Bureau had neglected the task of tracing the factors that constitute social inequality between impaired and non-disabled at societal level. The Bureau seems to assume that discrimination will be tackled overnight once law enforcement and education have changed people's attitude towards disability, and therefore, the commissioner needn't closely question the practices in social lives in many aspects that would cause discrimination against disability. An instance showing this view of the Bureau is that in July of 1998, the Commissioner of Rehabilitation took salary cut as a means to enhance the employability of the disabled people, but did not question the lowered salary level of the disabled. Therefore, salary disparity between disabled and non-disabled was considered as reasonable.

With regard to social policies, the rights of the impaired are put in the following ways: construction regulations require constructors to provide good access to people with impairments; tax exemption is offered to whose who live with and take care of the people with impairments; and special employment assistance scheme offers special assistance to impaired. Nevertheless, none of these policies could achieve social equality for the disabled. Thus, there were protests against limited access for disabled people in our community. Many people thought building additional access for the disabled people to prevailing premises as a matter of a waste of resource or a disturbance bringing forth noise and air pollution. It is clear that although construction regulations have been stipulated for the purpose of protecting the accessibility of the impaired and educating the common people, the achievement of this policy seems far behind its expectations.

Social services are also provided to the impaired, such as comprehensive social security scheme, home help service, rehabilitation service, counseling service, *etc*. However, the existing services make little improvement on the lives of people with impairments or provide more opportunities to the disabled people. Rehabilitation bus service is a case in point. The Hong Kong Society for Rehabilitation has only a few buses to meet the demands. Under this situation, insufficient provision led to 1500 rejected bookings each month. This is one of the major barriers to agency in carrying out programs and also it limits the opportunity for the disabled to participate in the programs. Clearly there are socially imposed restrictions on the impaired, and we should throw light on its constitution and impacts.

Review of literature on disability in Hong Kong

For the purpose of reviewing the literature on Disability in Hong Kong, I will employ a general framework to map out the academic efforts in this respect. The main concern in Hong Kong for disability could be deemed as revolving around inequality. Hence, I follow this line to depict the findings and arguments pertaining to the relationship between disability and inequality. I will here turn to presenting a general criterion of social inequality and then focus on the findings in Hong Kong.

Disability and inequality

We believe that social difference and inequality are generated from discriminated attitude in society. Sociologists indicate that social difference is related to social inequality. After the formation of social difference, groups are located into different social positions. However, social inequality occurs when one group is ranked above the others in society, social resources are allocated accordingly. Personal advancement will be thus determined according to their social positions and resources obtained. The consequences of social inequality may shape people's social status, prestige and power socially and delimit the resources they can obtain and use.

Social inequality is different from natural inequality; the former referring to the inequitable treatment that is originated from historically established human relationships. Human actions rather than natural born create it. In this study, I will investigate the factors shaping social inequality that would appear in terms of spatial, temporal and social aspects of socially imposed restrictions.

i) Spatial aspect

For effective social control and the establishment of self-identity of individuals, social difference has been produced and reproduced to maintain, or show, the boundary between groups in society. Spatial arrangement plays specific roles by its specific characteristics of manageable, creatable, planned and symbolical features. The function of creating and sustaining the boundary by spatial arrangement is to mark distinction. Moreover, boundary formation and maintenance are inherent in the functioning of society to locate different groups into different social positions. At individual level, the boundary formation can help people to exclude the invasion from others, and reap the benefits from controlling over surroundings. At least, in this way people within the mainstream feel safe and being protected. Spatial arrangement through the accomplishment of separation and exclusion in environmental design, usage and social setting reveals hidden social meanings like: same vs. difference, acceptable vs. unacceptable and welcome vs. resistance, *etc*. Such environments, where people are living, are a place that carries not mere physical implication without any social implications, but are positioned in a matrix of social relations.

With respect to the investigation of the spatial arrangement that is found to be exclusive, social service organizations have done a lot on the restrictions on the mobility of wheel-chair users. A study on playground accessibility was conducted in 1999, which showed the accessibility was unsatisfactory. As it was reported, '5 out of the 8 accessible entrances were at the main entrance of the park or estate. The rest of the 3 accessible entrances were not at the main entrance and there were no signs indicating the where about of the accessible entrance' (Yip 1999:39). In addition, of the two hundred and thirty pieces of equipment examined in the study, only seventy six (33%) could be evaluated by measure in terms of the ASTM-1487 standard, and only one-quarter of these (19 pieces out of 76, 25%) met all or most of the standard specifications. Another findings showed that one hundred and thirty-three (57.8%) had accessible routes to the equipment. Clearly the findings found the low inaccessibility of public playground sites for young wheel-chair users. Apart from this, public toilets are one of the major concerns in disability study. A survey conducted by Rehabilitation Alliance Hong Kong (1998) showed that the accessibility and equipment of public toilets in shopping malls, public housing estates, restaurants and buildings of various of Hong Kong Government departments. Out of one hundred and twenty-four toilets under observation, only eighty-two were accessible and only one was up to the standard stipulated in the "Design Manual: Access for the Disabled 1984" – an ordinance requiring constructors to observe the specific needs of people with impairments. These findings have clearly showed how seriously social restrictions are imposed on the people with impairments.

ii) Temporal aspect

The focus on the temporal aspect of social disability is the change of social acceptance of disabilities over time. Dear' *et al* (1997) indicated that there are three types of situations leading to the change of the hierarchy of acceptance to disabilities which include: 1) new groups have been added to the hierarchy, 2) the hierarchy has undergone relational shifts of groups within itself, and 3) the hierarchy as a whole has experienced a positive or negative shift. The change of the hierarchy of acceptance of disabilities leads to the change of treatments to disabled in society.

However, it is sad to see that there are few studies about the temporal changes of the hierarchy of acceptance of disabilities in Hong Kong. One finding in respect to changes was mentioned in a report issued by the Equal Opportunities Commission that 'as compared to the situation in 1987, there was a drastic shift in the number of employees with a disability from working in manufacturing industry to the community, social and personal services industry and wholesale and retail industry sectors. The previous research by the HKCSS

(1987) revealed that 48% of employees with a disability were working in manufacturing industry, while only 12% of respondents in this study were working in manufacturing industry, and 43% and 20% of them were working in community, social and personal services industry and wholesale and retail industry respectively" (Equal Opportunities Commission Hong Kong 1997:71). More academic efforts are certainly needed for showing the temporal aspects of disability in Hong Kong.

iii) Social aspect

The identity and boundary formations, as well as maintenance take place not solely in individual base but rather within a broader social context. Their formation and maintenance must relate to prevailing social systems, social norms and social attitudes. Thus, we may consider self-identity as the matter in social nature. Within specific historical and cultural contexts, social difference and otherness are formulated in the process of identity and boundary formation and maintenance. The consequence of identity and boundary formation is not only distinguishing "Self"/"Other", "Normal"/"Abnormal" and "Same"/"Difference", but also constructs mutual social relations. Under specific social relations, people's social status, resources, positions and even attitudes towards others categorize a minority group and create a sense of social difference that results in the marginalization and discrimination against the disabled. In the process of the allocation of social resources and social status the disabled are at a disadvantageous position. The disabled such as mentally retarded and people with mental illness are treated as risk groups and relegated to an inferior social position. In the workplace, the standard of good working condition is set from the view of non-disabled and people with impairments find it necessary to fit them into such unfavourable working environment. In respect of social security and medical systems, professional assessment is dominant in the decision making process for the allocation of services to patients. A series of top down concepts and criteria of ableism and normality underpins professional practices.

In this respect, the Equal Opportunities Commission conducted a baseline study on employment situation of persons with disabilities in Hong Kong. The results were that 'the median monthly employment earnings of the general population in 1997 were $10,000. Nevertheless, two-thirds of the respondents with hearing impairment, mental illnesses and mental handicaps received employment earnings below this median. Alarmingly, about 22% of respondents with mental illness and 31% of respondents with mental handicaps received employment earnings below $2,000 per month. In fact, it is believed that most of these respondents were employed as part-time or casual workers' (Ibid.:71). This study also found that the lower educational attainment of respondents with a disability was an important factor that caused their employment opportunities to be clustered in the elementary and clerical occupations. At the workplace, one-third of the respondents reported unfairness in the areas of salary, promotion, arrangement of work, application for job, and relationship with boss and colleagues (Ibid.: 74). The conclusion of this report, as could be expected, found that 'the respondents with a disability [are] disadvantaged in the open labour market both in terms of job seeking and maintaining employment' (Ibid.:75).

Another study is concerned with employment opportunities for people with impairments. It has reported that the employment ratio between people with impairments and the total number of employees of the non-governmental organizations and voluntary agencies, which had altogether employed sixteen thousands people, were merely 1.2% and 1.4% respectively (Cheung 2002). These findings also show the disadvantages of the people with impairments in job seeking.

iv) Social attitudes towards disability and disabled people

In our view, social disability, an indication of the existence of social inequality, is the products of a social construction process. The public plays a significant role in such process. Oliver (1996) indicated that we should shift our focus from the physical impairment of individual, to the social attitude or perception to the ideal form body prevailing in a society in order to understand the origin of disability. He pointed out that non-disabled being a powerful group enshrines an ideal form of human body, as the constitutive component of the Self conception, and those whose body shape is far from this ideal are regarded as the "Other". Once the boundary between "Other" and "Self" is drawn, the dualism of "normality" and "abnormality" is then constructed. This is the attitude of "normality" and "ableism". The idea of normality informs daily practice institutions and social relations that presume ableist as normal whereas the "Other" or the "Abnormal" refers to people with impairments.

There are few studies on the implications of the 'ideal body' to the people's attitudes towards disabilities in Hong Kong. The Equal Opportunities Commission (1998) conducted a survey on public attitudes towards people with disabilities. But the framework was largely conventional in the sense that only information on the public's perception of and attitudes towards disability equality or discrimination was collected. A specific feature of this study is the construction of disability equality indices by which we could have a glimpse of the people's attitudes towards people with impairments in Hong Kong. The final index is 0.5291, representing 'an average of 52.91% of the respondents perceiving that there is disability equality in Hong Kong' (Equal Opportunities Commission 1998:8).

If shedding light on people's attitudes towards groups of people with specific impairments, we can see that people with mental illnesses experienced negative perceptions of the other, particularly that of the females and elderly people (HKCSS 1996). Another report, however, showed that 'the younger population tends to have a more positive attitude towards the ex-mentally ill as compared with the impressionistic negative of the general population' (Ng and Chan 1994:37).

Nevertheless, despite these findings, we found that there was little information about the factors giving rise to the social restrictions on people with impairments. I attempt to show in this study that the questions as to risk management and the embodied experience of disability should be addressed in the field of disability studies in Hong Kong.

Risk management and its implications

In this study, I will employ the significance of the concept of risk management to the construction of social inequality. Kemshall (1997) claimed that risk has become a fundamental criterion for rationing purposes and is most evident in areas where concerns about accountability are uppermost. He argued that although risk has become increasingly central as an organizing principle for social services, there is without clear and concrete criteria for the calculation of risks and the boundaries of responsibility. The assessment and prioritization of cases in decision making in risk handling are greatly dependent on the operation of managerial discretion and professional judgment. Such considerations include: 1) Precision of prediction and calculation and 2) Dynamic among clients' needs, rights and risks, organization's responsibility and accountability, and 3) public attitude to disables or disability and related risks.

Another major significance of risk management is its forensic functions. The forensic function is a means of investigating situations 'that go wrong' (Kemshall 1997). Virtually, its primary function is to allocate blame. The importance of forensic function is particular to developing different types of blaming system that individual becomes accountable.

The notion of risk as well as the considerations of need and rights of clients, freedom of choice and self-determination in working with clients, especially with disables or handling the issue of disability, will trigger off much dynamics at different levels. For example, sex education to mental retarded students, ,community services for ex-mental illness patients, are needed to put clients' risk and community or society risk into considerations. Goodwin (1997) revealed that Department of Health in Britain adopted such policy making process:

> "individual decisions about discharge have a fundamental duty to consider both the safety of the patient and the protection of other people. No patient should be discharged from hospital unless and until those taking the decision are satisfied that he or she can live safely in the community, and that proper treatment, supervision, support, and care are available. (Department of Health in Britain 1994:2)" (1997:262).

It entails that risk assessment and risk monitoring are two aspects that we should take into consideration. With regard to the aspect of risk assessment, the core functions are making prediction and preparation. The function of prediction leads the practitioners or organization to know what negative outcomes will happen, the possibility of happening and in what ways or what forms they will happen. And, another function of preparation has the benefit for identifying the responsible unit to shoulder the obligation or allocation of blame appropriately, and to look for suitable responses and prepare resources for handling the case beforehand.

The levels of risk assessment include individual, organization and society three levels. For social services, the assessment of risk is not only concerning the interests of clients but also the credibility of organization and public attitudes towards risk. In the study of the purchase of alcohol for older clients of home carers by Herring and Thom (1997), it revealed the problem of balancing the rights of clients and risk management in service provision. The purpose of their study was to investigate the dynamics and dilemmas between risk assessment and considering the needs or rights and risks of clients on service provision.

Risk monitoring refers to the processes of risk handling in occurrence and future arrangement. The level of primary concern among clients, organization and society and the reasons of such prioritization reflect the orientation and criterions towards risk management. There is the same dilemma of balancing rights and risks of service provision in monitoring risk as risk assessment. However, we need to pay much attention on the impacts to different levels including clients, organization, and society, decision-making and the policy formulation. All these levels show the process and dynamics of social construction of inequality in risk monitoring.

Risk assessment, risk monitoring and risk-taking themselves have become key issues for social service practitioners to consider seriously in respect of managing risk. Risks are increasingly becoming embedded in organizational rationales and procedures for both the provisions of services and relationships with clients (Kemshall et al. 1997). It is obvious that the importance of risk to organization is due to the negative or adverse effects of risk rather than potential gain or loss.

To consider both the risks from discharge patients and needs and rights of them, conflicts and dilemmas will be created unavoidably. It is because the needs and rights of clients may be limited or sacrificed in risk management. Social workers as the practitioner in provision of social service also play a role in between the social attitudes to disables and risk management. It is worth studying what impacts creating to them in making decision, forming service policy and planning their intervention under the notion of risk.

Interaction between social attitudes and risk management

For the public accountability, professional practitioners are required to respond to public opinions towards disability and disables as part of dominant social discourse. Moreover, the professions are required to predict the risk and negative consequences in advance and make appropriate decision to minimize the effects, which become a social control agent. Such prediction is required to consider the interests and risks of different levels including levels of clients, organization and community. It is obvious that the prediction and management of risk are complicated with regard to consideration of the interests of different levels. And, the relation among social attitudes towards disables and risk management is also to be developed dynamically.

The dynamic relation between social attitudes and risk management may be expressed in two ways. Firstly, negative social perceptions towards disability and the impaired may perceive disability and the impaired as risk. This perception shapes the picture and set agenda to disability. It also creates pressure on professional practitioners in handling the risk perceived by public. However, the relation between social attitudes and risk management on disability is more interactive and dynamic. Although the practitioners are required to respond to social attitudes, they can reshape the issue and social perception through their power, status, knowledge and skill in risk management. Those practitioners as an agent in between, are able to make the risk be controlled and the social perception be shaped and reshaped. Therefore, we can see that the relation among social attitudes and risk management on construction of inequality is much interactive and constructed mutually rather in linear or static form. The role of professional practitioners in between plays as an agent to regulate the situation.

The study of how social workers and medical professionals, as professional practitioners, react to the public opinions in dealing with risk in working with disabled and how social disability and inequality to the impaired are produced socially in the process of risk management, are important in understanding social construction of social inequality. At present, few studies related to social construction of inequality to impaired people are carried out in Hong Kong. Hence, our study is significant as an exploratory study to examine the situation. In the next part, we are concerned with the following aspects of disability.

Embodied experience of disability

The following three types of impacts will be highlighted in discussion on this issue. Embodied experience, as inner feelings of individual, will be studied in a deep-going way. The aim of studying embodied experience tries to obtain in-depth information for interpreting the lives of impaired people and meanings of disability rather than dominant and professional narrative. Owing to unequal social status, different forms of inequality, as spatial, temporal and social, may impose on impaired people. I am not only concerned with how different forms of inequality affect the lives of the disabled, but also with the multiply effects of these inequalities to the disabled. I try to understand what problems that the disables face in lives, what they are informed from dominant narrative and what they feel in face of an unfriendly environment and their low social status. In the study, we want to explore the real experience of disables in lives.

Relation between people with impairments and professional practitioners

In Hong Kong, a high level of legitimate authority of professions has developed in society. Caring professions have acted as a vital agent in response to social attitudes and managing the risk of disability and disabled groups. To analyze the relations between disabled and professional practitioners in respect of social construction of inequality can help us to know the dynamic of their interactions. Moreover, the position and picture of practitioners in construction of inequality on people with impairments are also explored. There are increasing concerns about the rights and interests of disabled in Hong Kong on these few years. In addition, the situation of establishment of disables' or patient's organizations or groups is prosperous. However, we expect to understand how individuals react to the dominance of non-disabled's discourse. What kind of reactions and struggles have the disabled taken? We are interested in exploring these situations in the study.

Implications to professional practice

Social work and medical practitioner are the major professions in working with disables and provide institutional services to disabled people. We know that the relationship between these professions and disabled has closely interrelated. Under the professional authority and closed interactions, professionals have great influence on the construction of disability and disabled identity in society. This issue becomes more complicated because of the multiple roles and positions of professional practitioners. For example, social workers, as advocators, request for social changes for clients' rights and interests. On the other hand, as social control agent in rehabilitation and probation works, social workers follow the notion of normality and existing social norms in professional practices. In addition, under the pressure of risk management, social workers play multiple roles as both case worker and manager in practice and are required to consider different parties' interests. Hence, social workers' role or position in the process of construction of disability and inequality is as part of discourse in dominant narrative rather than outside the narrative.

In this study, our attention will be paid to services for disables, such as medical services, rehabilitation services; community care service and vocational training service. The observation will focus on the following three aspects: 1) objectives of the service, 2) approaches of the service, 3) worker-client/patient relationship in work, and 4) the role of professionals in risk management and service provision. Through these observations, I will try to show the picture of worker-client/patient power dynamic in work and identify the role of professionals in the process of social construction of inequality to disables.

Project significance and value

I propose the study of social construction of disability and its implications for the following reasons. Firstly, the discussion of social construction of disability and related theoretical development is seldom carried out in Hong Kong. However, in comparison with foreign countries, the related discussion and theoretical study are prosperous. Although there is more attention paid to the issue of discrimination against disables in society, the issue of social construction of disability is still excluded from social agenda. These situations cannot help us to have a deep understanding of the issue of social construction of disability and they cannot help to improve disables' social status in Hong Kong either.

Secondly, owing to closed working relationship between professionals and the impaired people, the perspective of professionals towards disability has great influence on constructing the identity and social position of the impaired people. However, professionals stress on developing assessment tools and caring methods rather than the issue of social construction of social inequality to disables. Professionals overlook their role in the process of social construction of disability. Moreover, facing the requirement of effective risk management, we concern about what impacts will be created on application of professional principles. This study benefits investigating the role of professionals in the process of social construction of disability and inequality and reviewing the dynamics between the professional practice and tension of risk management.

As a front-line social worker and volunteer of a disables' organization, I have a number of chances to work with disables and make sense of their experiences. I have personally experienced the social barriers and inequality to disables time and again in my assistance to running services and programs. These experiences are valuable to understanding disability and the feelings of the disables more concretely, which is quite different from interview or literature review. I hope that my experiences plus the disables' feeling sharing would make this study more fruitful.

Research methodology

The first part is literature review that includes two main areas that are on the sides of theoretical aspect, historical and experiential aspect. Through the review, individual model and social model have been discussed in detail. Moreover, the comparison between these two models is made which shows us with the orientations and contradictions among them on the theoretical base. At the end of this part, I will introduce the Thomas's analytical framework of disability. She sheds light on psycho-emotional dimensions of impairment and disability. With reference to Thomas's perspective, the issues of restriction to doing something and being as what kind of people for disabled people are both important. However, in the past, the issue of restriction to as being as what kind of people for the disabled was neglected in the study of disability. Thomas's perspective becomes the theoretical framework, which I have borrowed in this study

Furthermore, I try to illustrate the theoretical discussion and development of the theory of risk management in the second part of this section. By such illustration, on one hand, enrich our understanding on the rise of concept of risk in modern society, which, especially, changes traditional sense of danger to risk. Moreover, I introduce four major perspectives of risk which are: technico-scientific perspective, symbolic/cultural perspective, risk society and governmentality perspective. In this study, I focus on the question as to the response of the various responsible actors towards the increasing risk in routine lives.

The second part is about case study. For the purpose of understanding people's attitudes and experiences to the social construction of disability to disables in Hong Kong, qualitative approach had been adopted. Twenty people with physical impairments, fifteen of male and five of female, were interviewed with in-depth interviewing during September 2001 to August 2002. They have suffered from various impairments that include lower part impaired, triad or quadratic impaired. Some of their impairments happened since birth and others caused by suffering disease or accident in childhood or later. Age range of these interviewees was from about mid twenty to late sixty.

It is necessary to highlight the significance of case study. There are three dimensions I try to explore through the case study. Firstly, I try to explore the social attitudes towards people with impairment. The purpose is to try to understand the social attitudes, positive or negative, towards the impaired. Secondly, I investigate the relation between the social attitudes and the risk management. It is assumed that rules and regulations on risk management to a large extent respond to social attitudes towards disability and related risk. The balancing and prioritization among risks, needs and rights to three parties, namely clients, organization and community, will be stipulated. Lastly, the considerations of social workers and other professions in making the balancing and prioritization will be studied. The criterions in making balancing and prioritization reveal the attitude and dilemma in insisting clients' interests. Furthermore, the discussion of the role of the professionals in the construction of social inequality to impaired people will also be explored.

The interviewees were invited voluntary participation for interviewing through referral from Direction Association for the Handicapped, an organization for people with disability in Hong Kong. There was a declaration of commitment by researcher to keep data in confidential to the organization and individual interviewee. The interviewees had read the interview guide and thus consensus on the contents of interview was obtained in before. For the interviewees' convenience and feeling of comfortable, the place for interviewing was chosen by them. The places for interviewing included restaurant, park, shopping centre, conference room of the referral organization and home of the interviewees. At the beginning of the interview, the interviewees had been told that there was the right and choice to keep silence or to stop talking about any issue that they did not want to mention. Moreover, under request of the organization and individual interviewees, copies of thesis were promised to release to them. Except one, all twenty interviews were taken recording by MD recorder for transcript writing. In presenting interviewees' personal accounts, I have tried my most efforts to protect their identities by changing names, omitting characteristics of figure and other identifying details.

There were two expectations of the interviewees for this study, which I have been told. Firstly, they hoped that this study could enrich the non-disabled understanding on them and their lives. And, secondly, their voices and feelings could be heard and shared with others. Referring to these expectations, I had adopted narrative approach to handle and present the narrative materials. A number of personal accounts of the experiences of living with impairment and disability have been extracted from the interviews directly and originally. Of course, different lengths of extracts or personal accounts have been articulated into various scenarios or plots. The criterion of such articulation is whether answer the major issues and questions of this study directly or not. From that the pictures of various experiences of impairment and disability can be organized and disclosed.

For purpose of maximizing control over the personal accounts by the interviewees, I tried my least intervention and interruption in interviews and quoting narrative materials directly and without any edition. This approach brings out the thicker description and reliable data for the study. But, in another side, the approach may be criticized in different ways, which I will discuss in chapter 6.

Rich narrative materials not only provide solid foundation for this study but also inspire my thinking a lot. By the time of interviews, transcripts writing and selection of narratives, my plan of the study and even my pre-occupied understanding towards disability have always been challenged. To certain extent, I have changed my study plan especially on my attitude of the interview. But, the most important are the experiences of living with disability by the disabled which let me know about my limitation and inadequacy on understanding disability.

- End -

Chapter 2

Literature Review

In this chapter, I will review the models or perspectives on disability and present the theoretical framework to be employed in the following analysis of disability in Hong Kong. In the first section, I will examine the issues about the definition of impairments and disability. In the second section, I will examine the significance of the concept of risk in the study of disability. In the third section, I will introduce Carol Thomas's concern over the psycho-emotional dimensions of disability. This perspective offers many theoretical guidelines for the following analysis. The final section is a summary of the questions posed in this study.

The concept of impairments and disability

In the 1970s and the 1980s, the crux of the academic debates in the field of disability study was the disputes about the distinction between the individual/medical model and the social model. The advocates of these models have different interpretations of the concept of disability. The contribution of their discussion finally brought to the forefront of the political significance of making a distinction between impairments and disability. Apart from its implication to political action, in the academic field, the discussion has also highlighted the advantages and disadvantages of these models, the theoretically adequate questions to be posed in research, the foci of study about disabilities, *etc.*

There are different meanings of the concepts of impairments, handicap and disability suggested by the proponents of different school of thought. In the period when the medical model was dominant in academic field, these three words represented similar meanings and were interchangeable to a certain extent in routine usage. Until recent decades, disability theorists have tried to make these concepts analytically distinguishable. Hunt (1966), who has been a disability activist and theorist in Britain, started his challenge against the traditional notion of disability through editing the symposium - Stigma: The Experience of Disability in 1966, and suggested that disability came from negative attitude from people at large. He asserted that physical impairments were not crucial to the disabled whereas the relationship of impaired people with "normal" people was more influential. For Hunt, the concepts of impairment, handicap and disability obviously are value-laden and these specific terminologies mainly came from able-bodied orthodoxy. He argued that the traditional understanding meshed up the meaning of impairments with that of disability, and attributed the daily hardship of disabled people to impairment of function and its effects on each individual with impairments. However, hardship came from the fact that disabled people "are set apart from the ordinary' in ways which see them [the disabled] as posing a direct 'challenge' to commonly held societal values by appearing as 'unfortunate, useless, different, oppressed and sick' (Hunt 1966:146). Hence, he tried to shift our attention from the medical account of disability to the question of social environment in the production of disability. Through such distinction, the social meaning of disability was articulated and there also created a set of different language and analytical basis in discussion that becomes especially significant for the struggle for disability movement.

Before the appearance of Hunt's work, though many studies on disability had been done, most of these studies, as Oliver (1996) pointed out, were the products of the perspective of individual/medical model. In the medical model, disability is regarded as a serious individual problem and physical injury that layman is never able to overcome. The situation has changed in the recent decades as another perspective called social model or social discourse of disability has been suggested for studying disability. The proponents of social model of disability shifted the theme from the study of individual physical body conditions to the social conditions that impose social barriers and restrictions on people with impairments. Oliver claimed that the advocacy of social model was of significance because it led to overturning the dominance of medical model on disability.

In order to explore the tension between the medical and social models in disability, we are going to briefly present the general theoretical tenets of these two models on disability in the following parts.

a) definition of disability:

It is important to clarify the term of disability. Different definitions of disability carry concrete different meanings and they also inform public, professionals and disabled people about various understanding of disability. In other words, the concept of definition locates disabled people in different social positions, creates different images of them and thereby leads to different practices of the disabled. As the claim made in the Disability Net, the importance of definitions is: "From our experience of working in local government we have learnt that definitions of disability can influence the way in which non-disabled people respond to disabled people. That is a definition that can place limits not merely on what is possible, but what is 'thinkable' in an organization. This is particularly so when the definition is built into organizational policy, procedure and practice, and used in training sessions and guidance notes."

Oliver also put emphasis on the definition of disability. He claimed that "similarly the disabled people's movement has realized that definitions and terminology plays a significant role in their individual and collective disadvantage. Terms such as 'cripple', 'spastic' and 'mongol' are offensive when used to refer to a disabled individual. Others, which depersonalize and objectify the disabled community, are also considered unacceptable. Example includes 'the disabled', 'the deaf' or 'the blind'"(1998:14).

For defining disability, in the Disability Net, it is proposed that there needs a distinction between the definitions of impairments and those of disability. Impairment is then understood as an injury, illness, or congenital condition that causes or is likely to cause a loss or difference of physiological or psychological function. And disability refers to the loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers.

These definitions are different from those suggested by those who are theoretically informed by bio-medical knowledge. For instance, Townsend

(1979) mentioned the concepts of disability as individual's 'abnormality or loss', including (1) anatomical, physiological or psychological abnormality or loss, such as those without an arm or a leg, or who are blind or deaf or paralyzed; and (2) chronic illness which interferes with physiological or psychological processes, such as arthritis, epilepsy and schizophrenia (1979:686-87). Later, this kind of definition includes the inability to perform essential activities of daily life. Academic interests then revolve around the issue of measurement, the interpretation of essential activities and individual's service needs. There were few discussions about the necessity of making a distinction between handicap, impairment and disability. Not until the appearance of the influential intervention into the debate of the World Health Organization (WHO) did people be aware of the significant implications of making such a distinction. WHO, in its new International Classification of Impairments, Disabilities and Handicaps provided an explanatory document in which the key terms had been clearly defined. Impairment was regarded as 'any loss or abnormality of psychological, physiological or anatomical structure of action; disability referred to 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'; and handicap to 'a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role (depending on age, sex, social and cultural factors) for that individual' (WHO 1980:29). Falling in line with this way of thinking on the definition of disability was the vanguard organization in Britain, the Union of the Physically Impaired Against Segregation (UPIAS) which favoured the definitions that impairment is 'lacking part or all of a limb, or having a defective limb, organ or mechanism of the body'; disability is 'the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities' (UPIAS 1976).

We notice that in the 1970s three key concepts had been used, including handicap, disability and impairments. However, our discussion hereafter is confined to the concepts of 'impairments' and 'disability'. This change has a long history and we would not go into details. But Barnes (1999) has summarized the changes: 'as long ago as 1974, disabled people in the UK rejected the three-fold typologies of official definitions, such as the World Health Organizations International Classification of Impairment, Disabilities and Handicaps (WHOICIDH), for example. In its place they produced a two-tier construct: 'impairment', the biological condition, and 'disability', society's failure to address the needs of people with perceived physical impairments. What's equally important is that this definition was later modified and formally adapted by Britain's national umbrella for user led organizations: the British Council of Disabled People (BCODP) at its inception in 1981, and its international equivalent: Disabled People's International (DPI) at its first world congress in Singapore the same year. The original definition of impairment was limited to physical conditions, and it was later expanded to include all impairments – sensory and intellectual. This was in recognition of the fact that all physical conditions have psychological implications and that all intellectual impairments have physiological consequences. Also, these labels were imposed rather than chosen and they were politically and socially divisive. Because of assumed difficulties in translation at the international level, DPI initially opted for 'disability' and 'handicap' in place of impairment and disability. However, this has recently been reversed by DPI Europe, mainly because of the problems associated with the word 'handicap', and the ensuing conceptual confusion resulting from the use of the phrase 'people with disabilities'. Among other things, it's an implicit if not explicit denial of the disabling effects of a profoundly unjust social system, and a positive disabled identity." (Barnes 1999:578) While along this historical trajectory the two concepts replace the three-tier conception, difficulties concerning the definition of disability continued to exist.

If we compare definitions suggested by The United Nations and those by the World Health Organization in terms of the cause, nature, role, and attitude towards the disabled people and the society, we could see the following differences.

The United Nations has proposed a set of definitions. Impairment is "any loss or abnormality of psychological, physiological, or anatomical structure or organ which include defects in or loss of a limb, organ or other body structure, as well as defects in or loss of a mental function. Examples of impairments include blindness, deafness, loss of sight in an eye, paralysis of a limb, amputation of a limb, mental retardation, partial sight, loss of speech, autism."(http//www.un.org/) Disability is a "restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being"(Ibid). It describes a functional limitation or activity restriction caused by impairment. Disabilities are descriptions of disturbances in function at the level of the person. Examples of disabilities include difficulty in seeing, speaking or hearing; difficulty in moving or climbing stairs; difficulty in grasping, reaching, bathing, eating, toileting. Handicap is a "disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual"(Ibid).

Oliver (1996) pointed out that although World Health Organization's definition of social handicap seems the same as Union of the Physical Impaired Against Segregation's definition of disability, disabled people did not have the same view on this. With reference to the World Health Organization's definitions, there are few arrangements and natures adopted. Firstly, the distinction between various definitions expresses the linear casual relation among impairment, disability and handicap, that is, individual condition (impairment), impairment condition (disability) and social circumstance towards individual (handicap) respectively. It seems to indicate that impairment causes disability and that in turn leads to handicap due to incapability of performing normal roles in society. Disabled activists did not accept this linear relationship among these concepts.

Secondly, three terms of definitions are set on the basis of the dual concepts of normal and abnormal. The notions of normality and abnormality then serve as the basic assumptions about the 'right' frame of reference to make sense of individual's condition and their related behaviour. However, disabled people, measured in strictly statistical terms, are the minority, and therefore people would regard them as abnormal. Disabled people are then tarnished with a negative image. While this definition does not fall in line with the general arguments put forward by the medical model, both perspectives locate the disabled onto disadvantageous positions.

On the other hand, both definitions suggested by Disability Net and The Union of Physically Impaired Against Segregation (UPIAS) are: "Disability is the result of negative interactions that take place between a person with an impairment and her or his social environment. Impairment is thus part of a negative interaction, but it is not the cause of, nor does it justify, disability." It is clear that the definition of impairments put forward by Disability Net and UPIAS rejects bringing any negative social meaning or implications to impairments. Neither individual tragedy nor physiological or psychological condition is said to be the causes of disability, instead social and environmental barriers matter. The definition suggested by the Disability Net has made this argument clear: "physical functions such as sitting, or bending, or reaching may be inhibited by impairment. But the inability to use public transport is not the result of a 'physical or a mental condition'. It is well documented that many disabled people cannot use public transport because it is not designed to meet their needs - either physically or organizationally."

However, in the Disability Net, it has been pointed out that there is a paradoxical situation trapping the disabled people in unfavorable social circumstances. The viewpoint of the Net is a critique of the malpractice of the Disability Discrimination Act in Britain. It is argued that "the more serve the affect of your impairment on your ability to carry out 'normal day-to-day activities' the more you deserve to have legal protection against discrimination". The problem of this approach is that the disabled people are forced to show their incapability of participation in society for the sake of obtaining the right to participate. In short, the activists in disability movement deny a link between impairment and the right of citizenship. However, in the 1990s, there arose a view critical of the absence of study of the role of impairments in understanding and tackling the issue of disability. In order to understand this debate, we shall first elucidate the social model and see how it makes sense of the issue of disability.

b) the medical model and the social model of disability

In order to reveal the political implications of the dominant bio-medical knowledge in treating people with impairments, Oliver suggested the social model of disability and compared it with the medical model. His theoretical tenets about the social model could reflect the significance of a 'politically correct' definition of disability that has been presented in previous section.

To make the distinction between individual model and social model on disability, Oliver pointed out that "there are two fundamental points that need to be made about the individual model of disability. Firstly, the individual model locates the 'problem' of disability within the individual and secondary it sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability"(1996:32). Looking at people with impairments from this model, functional limitations become the defining characteristic of an individual, being categorized as 'invalid'. Impaired people are said to have functional incapacity and need help to cope with their impairments. Consistent with the 'personal tragedy' approach, people with impairments are seen as victims, dependent on other's care and attention, and as those who are in need of expertise knowledge and intervention. Clearly the individual model provides intellectual ground for the contemporary welfare state to design specific program for helping impaired people to cope with daily activities. This in turn justifies the intervention of experts into the private life of impaired people. Barnes *et al.* has stated succinctly that 'in the individual model, the definition of disability as a medical problem presumes a corresponding solution and so encourages the domination of disabled people's lives by a vast army of allied professionals' (1999:25).

The second point suggested by Oliver is in fact a theoretical tenet at the heart of the social model. Oliver stated: 'the genesis, development and articulation of the social model of disability by disabled people themselves are a rejection of all of these fundamentals. It does not deny the problem of disability but locates it squarely within society. It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization' (1996:32).

With reference to the social model, we can see that nothing but the intangible restrictions imposed on and the tangible social barriers to the disabled create disability. Restrictions are not only limiting the advancement of individual but also systematically treating the disables as a minority group in society. Oliver emphasized that there is no causal relationship between impairment and disability.

In his view, while impairment should be studied by medical practitioners, disability falls into the field of sociology of disability. Moreover, as disability is the outcome of the erection of social barriers to people with impairments, political actions are required to overturn the barriers. Disability is not only an academic issue but is also related to political movement. In the past decade, disability movement led to a lot of amendments of the reference to physical impairments. Most importantly, the understanding of disability was put under a new light and the growing popularity of the social model results in more academic studies. Shakespeare maintained that 'the achievement of the disability movement has been to break the link between our bodies and our social situation and to focus on the real cause of disability, i.e. discrimination and prejudice' (1992:40). To annihilate the dominance of individual model, the proponents of social model took a pragmatic tactic by locating the issue of disability in the social domain and pressing for changes through collective identity and action.

To compare the differences of the models of disability, Oliver highlighted the key differences as shown in the table below:

Table 2.1 Differences between the individual and social model

The individual model	The social model
♦ Personal tragedy theory	✧ Social oppression theory

♦ Personal problem	✧ Social problem
♦ Individual treatment	✧ Social action
♦ Medication	✧ Self-help
♦ Professional dominance	✧ Individual and collective responsibility
♦ Expertise	✧ Experience
♦ Adjustment	✧ Affirmation
♦ Individual identity	✧ Collective identity
♦ Prejudice	✧ Discrimination
♦ Attitudes	✧ Behavior
♦ Care	✧ Rights
♦ Control	✧ Choice
♦ Policy	✧ Politics
♦ Individual adaptation	✧ Social change

Source: Oliver, M. (1996) Understanding Disability: From Theory to Practice. *Hampshire: Macmillan Press Ltd. p. 34.*

Although it is too simple for a complex reality, this framework of bipolarity helps us to locate the issue easier and clearer. To conclude the discussion in disability, medical/individual model locates the disability issue on physical and individual basis on which personal tragedy is drawn eventually. This claim attracts serious critiques and responses from social modellists, with an aim to trace the cause of disability to social environment that means, social barriers.

The proponents of social model of disability stress on collective identity and the need for struggles for change. They were also eager to pinpoint the social meanings of the production of disability and regarded impairment as a physical matter. They dichotomized the reality into the natural domain that pertained to impairments and the social domain to social nature of disability. This theoretical arrangement although strengthens the basis for struggle in social movement, nevertheless it is not enough for the provision of theoretically informed framework to understand the nature of multi-oppression and the link between disabling experiences in lives and other forms of oppression. Moreover, the lack of critical examination on the social construction of impairment, which differs from the handling of the concept of disability, not only discloses inconsistency of the model but also lowers its convincing explanation of relationship between impairment and disability.

Despite a vast range of challenges towards the social model, the fact that the social model gained increasing attention went hand in hand with the success of disability movement in many domains. In the past decades, the Independent Living Movement (ILM) in America sparked off a series of social action, focusing on rejecting 'the behavioural expectations of child-like dependency assumed by professional rehabilitation experts, which gained full force in institutional settings. Instead, it was argued that environmental factors are at least as important as impairment-related variables in assessing the capacity of a disabled person to live independently' (Barnes, *et al.* 1999:68). The ILM swept America during the 1970s by pursuing the interests of the people with impairments through the economic and political marketplace. In the view of many disability scholars, the social model heralded a new politics of disability. Hahn (1988) insisted that traditional approaches coached in biomedical terms adopted an analysis that denied that disability is properly the subject of public policy intervention, while the socio-political orientation of the social model advanced a justification for exploring an alternative environment shaped by political protest by disabled people and imaginative and radical, policy changes. Albrecht identified an interesting phenomenon and argued that the social construction of disability had been accompanied with the growth of a massive rehabilitation industry. He went further to advance a political economy model of disability to focus on 'the political economy of a community [that] dictates what debilitating health conditions will be produced, how and under what circumstances they will be defined as disabling, and ultimately who will receive the services' (1992:14).

Barnes *et al.* summarized the influence of the social model in the academic field. They marshaled evidence to support their view that they "confirm the existence of systematic inequalities between disabled and non-disabled people. This experience of discrimination spans education, employment and the built environment, including housing and transport. It extends from these 'public' domains to the more 'private' sphere of family life, and moral issues about what sorts of lives are valued and devalued. Although the amount of research on disability as it affects different groups of disabled people is limited, it presents a common picture, with the impact of gender, ethnicity, and age all mediating the experience of disability in specific ways" (1999:123).

I have highlighted the main theoretical tenets of the social model and pointed out its contribution to the understanding of the social nature of disability. However, in recent years, two issues have arisen with the foci on the significance of the concept of risk on the one hand and on the implication of the disappearance of body to the new direction of disability study on the other. We shall first review the concept of risk and find out the extent to which this concept can inform us about the study of disability in Hong Kong. In the ensued section, we shall focus on the debate about the importance of the sociology of embodiment.

The history and changes of risk in society

The issue of risk is associated with the technico-scientific perspective, symbolic/cultural perspective, risk society and governmentality perspective. It is important to explore the links between these perspectives and their different levels of rationality.

Lupton has borrowed Muchembled's idea to point out the meaning of risk in society. She claimed that "societies develop a system of strategies and beliefs in the attempt to deal with, contain and prevent danger. To lack such system is to throw oneself upon the mercy of fate, to relinquish any sense of control. In contemporary western societies, where control over one's life has become increasingly viewed as important, the concept of 'risk' is now widely used to explain deviations from the norm, misfortune and frightening events. This concept assumes human responsibility and that 'something can be done' to prevent misfortune" (1999:3). Although there are different forms of fear, different targets and causes for anxiety in contemporary society, the symbolic foundation of our uncertainty is rested on disorder and the loss of control in various aspects of lives.

A number of scholars link the emergence of the word and concepts of risk with maritime ventures in the pre-modern times. Lupton (1999) adopted Ewald's claim and argued that the notion of risk appeared in the Middle Ages firstly for maritime insurance. At that time, risk was treated as a natural event as storm, earthquake or epidemic rather than a human fault. Under this perception, there is no or little human responsibility to risk but people only try their efforts to estimate roughly and reduce the impact.

The concept of risk had changed by the coming of Enlightenment and Industrial Revolution to the seventeenth-century. The dream in Enlightenment was human progress and a belief in the demythical function of knowledge and rational thinking to tease out the inherent nature of the physical and social world. Truth and order of the world can be obtained and controlled by human. For this perceptive, risk seemed no longer as fate or natural event. Risk becomes a matter that can be known, understood, measured, predicted and even calculated by the scientific knowledge. And, Lupton argues that 'During the eighteenth and nineteenth centuries, the early modern European states sought to harness their populations productively and deal with the social changes and upheavals wrought by mass urbanization and industrialization as part of the Industrial Revolution' (1999:6). The advancement of mathematics in probability and the development of statistics provided the intellectual tools for rational counting of risk. Rational thinking and bureaucratic system development under the processes of industrialization and capitalization in western countries provided a new way of viewing risk in the world. The attached or related meanings as fate or fortune at risk in pre-modern era are eliminated by rationality and bureaucratic management during modern industrial period. In other words, the invention of new concept of risk in modern time has both got rid of indeterminacy or uncertainty but also transformed the world into manageable by the belief of rational calculability. Such transformation especially and directly benefits the expansion of insurance industry because it makes the thing or event become much countable, calculable and compensatory in terms of money.

Giddens also shared a similar view to risk. He claimed that 'life in the Middle Ages was hazards; but there was no notion of risk and there doesn't seem in fact to be a notion of risk in any traditional culture. The reason for this is that dangers are experienced as given. Either they come from God, or they come simply from a world, which it takes for granted. The idea of risk is bound up with the aspiration to control and particularly with the idea of controlling the future' (1998:25).

Douglas (1992) further pointed out that 'the word risk now means danger; high risk means a lot of danger' (1992:24). This situation happens especially in the case of technical assessment of risk. As quoted by Lupton, 'While risk-and-cost benefit analyses of focus on both positive and negative potential outcomes, benefits tend to receive short shrift in these analyses, as do positive aspects of risks' (Short 1984:711). That means, in economic speculation or calculation, the greater risk with greater return and vice versa. This negative tendency in using the word risk also reflects in everyday lives of lay people. Lupton (1999) indicated that 'risk means somewhat less than a possible danger or a threat, more an unfortunate or annoying event'(1999:p.9).

In recent decades, the concept of risk is commonly used in expert researches and has developed various related concepts such as risk analysis, risk assessment, risk communication and risk management. Major objective of the usage of concept of risk tends to measure and control risk in a wide range of fields which include medicine, public health, insurance, finance, business and industry. These researches activities have scientized the concept of risk and created its knowledgeable basis in society. The survey of the use of risk in newspaper, which was held by Lupton, reveals that the use of risk in the main text and headlines of all articles published over the six years spanning 1992 to 1997 has become more of a key word in newspaper (Lupton 1999:10). The findings showed that the word of risk had replaced the older terms hazard, danger and threat in mass media and confirmed that knowledgeable and calculable elements of risk represent uncertain matters in society.

The Royal Society (1992) published reports to discuss the issues of risk in 1983 and 1992 respectively. Identification, quantification, management and organizational arrangement of risks were concerned in the reports. Moreover, the latter one tried to update the issues of public perception of risk and related considerations. The reports used the cognitive science or techno-science perspective to view risk issues. These reports laid the foundation and as a sample for scientific research on risk.

The previous summary of the recent development of the investigation of risk shows the tendency of using technical knowledge in the relevant field. Beck, however, contrasted what he saw as the two major approaches to interpreting risk, namely the 'natural-scientific objectivism about hazards' and the 'cultural relativism about hazards'. Whereas the former has been much discussed in academic and commercial fields, the latter appeared to be left unattended. Beck (1995) pointed out that the natural-scientific objectivism about hazards did not exhaust the forms of risk-perception and risk-management in modern societies. Furthermore, only a few scholars were interested in understanding the value and signification of the cultural relativism about hazards. Beck was of the opinion that "neither experiments nor mathematical models can 'prove' what human beings are to accept, nor can risk calculations anyway be formulated solely in technological-bureaucratic terms, for they presuppose the cultural acceptance they are supposed to manufacture; (1995:91). He further argued that risk calculations 'are now no longer thought of as arbitrators but as protagonists in the confrontation, which is enacted in terms of percentages, experimental results, projections, etc.' (1995:92). Beck is interested in the 'cultural disposition' revealed by individuals and social groups to determine which risks are important while others are ignored. To him, in modern societies, the hazards, which come under the public focus, are principally environmental problems such as air and water pollution, ionizing radiation and toxic chemicals in foodstuffs. These risks however are determinable, calculable uncertainties. In other words, risks and threats are transformable into the forms that knowledge could help to master and control. In the late modern era, the foundations of risk logic changed in the direction of the growth of incalculable risks that could bring into non-localized and long-term effects. Of course, this conception arose from the experience of Chernobyl catastrophe and seems to be associated with the concerns of the natural-scientific objectivism about hazards. But if we extrapolate this experience to our concern with AIDS, we can say that incalculable risks and threats also exist in our daily life. Thus, epidemics of bacterial infections and the related diseases turn out to be incalculable risks given that many new types of virus have not been thoroughly researched and controlled.

By knowing the dominance of medical model of disability, we believe that people would link bacterial infections with disability. Moreover, the ignorance of the causes of disability results in a problematic idea of the possible infections from disability. People then avoid having any contact with impaired people. If this interpretation is correct, people on the street may prevent themselves from communicating with impaired people. We surmise that the more uncertain about the possible hazards of impairments the more likely the people avoid interacting with impaired people. This interpretation is reasonable as Lupton (1999) pointed out: 'It is clear that many aspects of people's lives are influenced by their awareness of risk and the responsibilities involved with avoiding risks. It is also evident that individualization, which emphasizes personal responsibility for life outcomes, is dominant in late modern societies. Many people appear to have accepted the notion that one should make oneself aware of risks and act in accordance with experts' risk advice so as to prevent or diminish the impact of risk. Indeed the notion that one is personally responsible for the control of risk appears to be acculturated very early in life' (1999:107).

c) The disappearing Body in the sociology of disability

Apart from the suggestion of the integration of the concept of risk to study the erection of social barriers that are said to be the components giving rise to disability, we also attempt to illustrate the need for a sociological approach to impairment. Hughes and Paterson (1997) entered into a theoretical lacuna that impairs the social model of disability with respect to its treatment of embodiment. This needs arise from specific treatment of body and impairments in the social model of disability which is said to have 'conceded the body to medicine and understands impairment in terms of medical discourse' (Hughes and Paterson 1997:326). When the social model was suggested in the 1980s, disability was understood not so much a consequence of physical dysfunction as that people with impairments were disabled by a social system which erected barriers to their participation. Shakespeare proclaimed that with the rise of social model, 'the achievement of the disability movement has been to break the link between our bodies and our social situation and to focus on the real cause of disability, i.e. discrimination and prejudice' (1992:40). According to this model, any discussion on body, bodily experience and impairments risks consigning the bodily aspect of disability to the space dominated by bio-medical practice. Shakespeare warned us that 'to mention biology, to admit pain, to confront our impairments has been to risk the oppressors seizing on evidence that disability is really about physically limitation after all' (Ibid.:40). Oliver (1996) and Barnes (1991) argued that the personal experience of living with impairment is not the concern of disability studies, and that intellectual and political efforts should be invested on understanding the wider social causes of 'disability'. Oliver maintained that 'ironically that is precisely what the social model insists, disablement is nothing to do with the body. It is a consequence of social oppression. But the social model does not deny that impairment is closely related to the physical body. Impairment is, in fact, nothing less than a description of the physical body.'(Oliver,1996:p.35) And 'the social model does not deny that some illness may have disabling consequences and many people have illnesses at various points in their lives. Further, it may be entirely appropriate for doctors to treat illnesses of all kinds, though even here, the record of the medical profession is increasingly coming under critical scrutiny. Leaving this aside, however, doctors can have a role to play in the lives of disabled people: stabilizing their initial condition, treating any illnesses which may arise and which may or may not be disability related.'(1996:pp.35-36)

As a result, social modellists focused heavily on socio-structural barriers but downplayed or even ignored the cultural and experiential dimensions of disablism.

In view of the lack of theorization of impairments, some studies of disability criticized the social modellists of its totally neglect of the substantive painful experience of impairment. As the social model rejects any possibility of embodied experience in the disables' lives. Morris pointed out that 'there is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability - and do indeed disable us - to suggest that this is all there is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying (Morris 1991:10)'.

Facing the critique of the denial of the pain of impairment, Oliver and Shakespeare gave their reply to the concerns of the disability movement. They considered that the achievement of the disability movement has been to break the causal relationship between bodies and social situation. The focus should fix on the real cause of disability such as discriminated social practices and prejudice. Shakespeare argued that there is risk to prove that disability actually comes from physical limitation if we try to mention biology, to admit pain and to confront impairment.

Although the vital inquiry into social model did highlight social environment as real and the origin of disability, there is no critical examination on impairment at the same time. Szasz's study (1990) of mental illness illustrated the significance of the study of impairment. Also Barnes, *et al.* (1996) pointed out that mental illness was a myth in society, just as a metaphor for problems in living. Mental illness is a moral judgement. Szasz further indicated that 'diagnoses are social constructs that vary from time to time and from culture to culture'.(Barnes, Mercer and Shakespeare (ed.), 1999, p.61) This was revealed in the fact that the Disabilities Act 1990 in America included as mental illnesses: 'claustrophobia, personality problems, and mental retardation', but excluded 'kleptomania, pyromania, compulsive gambling and transvestitism'. Barnes, *et al.* (1996) argued that this division showed the arbitrariness in the diagnosis of mental illness and was associated with economic, political, legal and social considerations.

Barnes, *et al.* (1996) believed that this argument had opened up a sociological debate to disability theory. The notion of 'mental illness is a myth' challenged the social modellists who left the task of understanding impairments to medical profession. Oliver (1996) insistently denied the causal relationship between impairment and disability. However, it seems unconvincing. It is because given that the social model leaves room for medical professions to define the nature of impairment, that is equal to accepting or permitting the authoritative bio-medical profession to exercise their power, apply their knowledge and mark impaired people as the 'other'. Such a view on impairments seems to adopt the view that impairment is a matter of natural and biological thing in nature and condition. Hence, the significant and even dominant role of medical profession in dealing with the issue of impairment may become reasonable and unquestionable. The stand of social model, therefore, becomes quite contradictory. The concept of impairment refers to something related to physical or biological basis, and the concept of disability refers to a product of social oppression. This shows inconsistency within the social model in differentiating these two concepts.

In order to construct an embodied framework of disability study, we should focus on the bodily experience of impairments. We shall present the social model of disability in the next section and illustrate the significance of the distinction between disability and impairment, and further point out the importance of the study of the psycho-emotional dimensions of disability and that of impairments.

d) Towards a sociology of impairment: the psycho-emotional dimensions of disability

We recapitulate here, as shown in Figure 2.1 the argument of the medical and social models and see how a new strand of materialist social model has entered the theoretical lacuna of social model of disability. In medical model, the individual's impairment causes disability. It is the difficulty of individual functioning with physical, sensory or intellectual impairment that engenders the problems of disability. Curing impairments is equivalent to the elimination of disability. Thus, in some versions of medical model, the concepts of impairment and disability are interchangeable. In order to deal with the people with impairments, the general solution is to help the impaired people to adjust to their limitations. Nevertheless, this model individualizes disability and ignores the socially created restrictions on individuals.

In the social model that is proposed by the leading social modellists, disability is caused by the restriction of activities through the erection of social barriers. Political activities aimed at the demolition of socially created social barriers including physical barriers (Zarb 1995; Imrie 1996); the organizational and attitudinal barriers (Barton 1996; Corbett 1996; Riddell 1996); barriers in leisure and barriers preventing impaired people from fully participation in civic and political structures and process (Barnes 1991; Zarb 1995). The critiques of the social model brought out the issue of the cultural and experiential dimensions of disablism and the significance of impairment itself. Thomas's contribution to the development of the materialist strand of the social model is that she acknowledged the political and conceptual significance of the social model.

Figure 2.1 Causal Factors of Disability

Medical model	Impairment → disability
Medical model	Impairment = disability
Social model	Social barriers → disability
Materialist social model	Social imposition of restrictions of activity disability → disability

The variant of the social model suggested by Thomas has an important distinction between the property approach and the social relational approach to the definition of disability. Social modellists commonly use the property approach to the definition of disability. It is actually a variant of the ICIDH definition, that is, disability is a property of the person with impairment: 'a disability is any restriction or lack...of ability to perform an activity', or disability amounts to 'restrictions of activity experienced by people with impairment' (Ibid.:41).

The social relational approach to the definition of disability, as suggested by UPIAS, refers to 'the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have...impairments and thus excludes them from the mainstream of social activities' (Thomas 1999:40). In this view, disability is a social relationship between people, or put it in other ways, disability equals the social imposition of restrictions of activity on impaired people. Thomas stressed the 'social' impositions of restriction of activity on impaired people.

Thomas reminded us of the possibility that not "all disadvantages or restrictions of activity experienced by people with impairment constitute 'disability'. That some restrictions of activity may be directly associated with, or 'caused by', having a physical, sensory or intellectual impairment (not being able to do certain things because of the absence of a limb or the presence of chronic pain or fatigue, for example) is not ruled out – it is just that these are not 'disabilities'" (Ibid.:42). This idea led Thomas to conceptualize those restrictions of activity, which do not constitute disability. She suggested the concept of impairment effects. As Thomas argued, "in a society in which the dominant discourses attribute all restrictions of activity to the 'tragedy' of impairment, it is of great political significance to conceptually separate out disability from impairment effects'" (Ibid.:43).

Impairment effects in the sense that 'the restrictions of activity which are associated with being impaired but which are not disabilities in the social relational sense. Impairment effects may become the medium of disability in particular social relational contexts' (Ibid.:42) She did not see impairment effects as the effects of the biological or the natural, or as a pre-social phenomenon. These effects are profoundly bio-social, being the outcomes of the interaction of biological and social factors as well as being bound up with processes of socio-cultural naming. The interaction of disability and impairment effects constituted the 'lived experience' of people with impairments as a holistic entity. Lived experience is the product of such an interaction, which constitutes the personal experience of the impaired people. As Thomas maintained, 'the lived experience of many people with impairment in society is shaped in fundamental ways by the interaction between, and the accumulative impact of, disability (disablism) and impairment effects. However, a careful analytical distinction needs to be made between the consequences of disability and impairment effects. The most fruitful way forward is to develop an approach which understands disability as a form of social oppression, but which finds room for the examination of impairment effects' (1999:156).

Thomas suggested a simple typology for the study of disability and impairment effects. She argued that 'disability and impairment effects each have two dimensions which interact: first, factors and processes which serve to restrict activity ('doing'); and second, factors and processes which undermine psycho-emotional well-being ('being'). It is necessary to study both dimensions, giving a 2 x 2 matrix' (Ibid.:157). We produced her matrix in the Figure 2.2.

Figure 2.2 Thomas's Analytical Framework of Disability

	Restrictions of activity	Impact on psycho-emotional well-being
Disability	√	√
Impairment effects	√	√

Source: Thomas 1999:157.

I need to briefly explain three concepts used in this analytical scheme. Informed by the social model of disability, studies of disability have examined the erection of social barriers and see the extent to which the activities of impaired people are restricted. In order to study this aspect of disability, they are concerned with what the impaired people do and how the impaired people are prevented from doing and acting. This aspect is what Thomas means 'doing'. This is also our concern as stated in the upper-left bracket in Figure 2.2.

With a view to broadening the scope of study of the social imposition of restrictions of activity on impaired people, Thomas suggested a move forward to understand the extent to which social imposition of restrictions on activities has shaped the impaired people's personal identity, subjectivity or the landscapes of their interior world. This is to discover a path towards the psychological and emotional domains of impaired people. Thomas referred these inner domains as the psycho-emotional dimensions of disablism (1999:46). The psychological and emotional state of impaired people is associated with the personal identity and subjectivity. Thus, the focus is on the questions: 'who are we?', 'how are we prevented from being?' and 'how do we feel and think about ourselves?' These questions are related to the 'being' aspect of the impaired people. This is also our concern as stated in the upper-right bracket in Figure 2.2.

Nevertheless, apart from the psychological and emotional state of disability, I also concerned with the psychological and emotional dimension of impairments. The psycho-emotional impairment effects are significant since 'they play a part in many disabled people's lives, and have to be understood in social and not just biological terms. Thus, in the same way that disability both restricts activity and has psycho-emotional dimensions, so too do impairment effects (Thomas 1999:47). Impairment effects are the direct effects of impairments, which differentiate bodily functioning from that which is socially construed to be normal or usual. These impairment effects generally become the medium for the relational enactment of disability: social exclusionary and discriminatory practices (Thomas 2002:20). Here we incorporate the theoretical concern, as suggested by

Marks (1999), about the biological, social, relational and unconscious level of analysis. Marks' concern is based on Wendell's findings of the monopoly of medicine and as a result, "the patients account of their experience came to be seen as having little bearing on an 'objective' diagnosis or treatment strategy" (1999:6-12). Wendell also found that by monopolizing 'cognitive authority', medicine subjects disabled people 'to possible private and public invalidation by others…it has a tendency to ignore, minimize the importance of, or deny outright any…bodily experiences that it cannot explain' (1996:122). In view of the monopolization and dominance of bio-medical knowledge, the patients are regarded as a docile and passive body. Obviously, patients are not agency. However, Martin (1989) showed in her study that people were not passive, being totally submissive to medical authority. She found that many female patients did give phenomenological accounts of their bodies. These were based on their own experiences of the lived body as it blended in with more informal advice and received wisdom passed on by other women. I interpret this as the outcome of the resistant mounted by the people. These findings provide evidence for us to argue that impaired people are not passive in interpreting their own feelings. In reporting and understanding their impairments, the impaired people have their own views that are, in some situations, contrary to those suggested by the medical authority. It is here that struggles take place. And in our view, the experience and outcomes arising from this kind of struggle are 'social' in nature and constitute the psycho-emotional dimension of impairments. This is the area as stated in the lower-right box in Figure 2.2. Of course, we know that it is important to study the restrictions on activities due to impairments. This aspect is not as important as its psycho-emotional dimension.

In this chapter, I have elucidated the implications of the definitions of disability. I agree to the distinction between disability and impairment, and gave up using the concept of handicap. I also tend to accept the social model instead of the medical model since the latter attributes disability to personal tragedy. The medical view leads to the ignorance of the restrictions socially imposed on impaired people and its result in social injustice and discriminatory practices. The social model, however, commits to political advocacy and the destruction of social barriers, without giving sufficient attention to the impairment effects on the psychological and emotional dimensions of the impaired people. While focusing on the social restriction, the social modellists leave unattended the dominance of medical practitioners in respect of the interpretation of personal feelings arising from impairments. This view also neglects the possibility of political struggles between the impaired people and the medical authority at the personal level. In other words, the political and theoretical significance of the feminist slogan 'personal is political' has not been taken seriously. In this study, I draw heavily on Thomas's theoretical framework of disability study and incorporate the concern with the challenges of the impaired people against the dominance of bio-medical views. The results will be presented in the following chapters.

In the next chapter, I will focus on the impacts of the socially imposed restrictions on the activities of the wheel-chair users. With specific attention paid to the concept of risk perception and risk management, I attempt to provide a middle-range theory to account for the experience of this kind of impaired people in their everyday life. In Chapter 4, I will examine the psycho-emotional dimensions of disability. The findings are mainly drawn from the personal narratives of the wheel-chair users so as to show that human service professional, medical practitioners and even family members of the impaired people act in a way to pressurize the impaired people to act as conformists. However, their activities on the impaired people produce negative effects on the well-being of the impaired people. In order to live gracefully, the impaired people react against the social pressure acting on them. Chapter 5 is an analysis of the psycho-emotional dimension of the impairment effect, with specific focus on the interaction between medical practitioners and the impaired people. I will attempt to argue that it is a site in which the impaired people challenge the dominance of the bio-medical knowledge and practices. Chapter 6, the last chapter, is the conclusion. In this chapter, on one hand, I will summarize the major issues and findings of this study. On the other, theoretical implications of the study, suggestions for future study and policy implications will also raised.

- End -

Chapter 3

Management of the disabled population

Introduction

This chapter is to examine the ways of risk management of people with disabilities. It is quite common that people with disabilities are looked upon as the 'other' or being 'abnormal'. Negative image is thus shaped on those people whose physical and physiological features are different from the so-called 'normal' people. In other words, physical, psychological or psychiatric impairment turns out to be the marker signifying 'abnormality'. Such marking shows or reflects the reality of a man-made demarcation line between the so-called normal and abnormal in social life. It also provides the objective elements by which social attitude of acceptable and unacceptable body structure emerges. As a matter of fact, in social life while people look at abnormality and otherness with a strange eye, they would have the feeling of fear and anxiety at the same time. We sensitize ourselves to the appearance of the "other" who is to a large extent physically or behaviourally different from us. Moreover, in modern society where rational control and management is appraised as the effective means to maintain proper social order, we are constantly on the alert and concomitantly put much effort on control and management of the 'other'.

The control and management of the "other" could be achieved in two ways. Public control through the state and medical practitioners become popular after the rise of the welfare state. Another feature of management of disability that draws our attention, is the increase in the promotion of self-management for people with disability. Benson (1997) mentioned that in discussing the medical and popular discourse of health, the management and enhancement of the body itself: the problem of how to shape it, how to defend it against illness and stress, how to decide what should be taken into it as food or drink, relates to the central issue of control in representing body and self. She indicated that fear of sickness or threat of bodies out of control has drawn people's attention on bodily control in contemporary western culture.

There have arisen specific ways to deal with the faulty or impaired body. Peterson and Bunton (1997) adopted Foucault's work to elucidate the modern forms of management of the 'others'. They maintained that "[T]he analysis of 'bio-power' gives us two axes through which power works in relation to the human body: one working on the individual body, the so called 'anatomo-politics of the body'. The other as a bio-politics of population' working through population" (1997:5). Such an approach to the body is not so much natural nor neutral but as to be reproduced in specific sets of practices and discourse. Their approach has drawn the attention to the techniques used for managing populations or the social body and particularly the 'apparatus of normalization' (Armstrong 1983: 51). Gastaldo (1997) examined the important role of health education in the execution of bio-power on management of social and individual bodies. He pointed out that groups of population and individuals are under the influence of bio-power, which is achieved by the design of sets of practices and various techniques going through in social life to carry the managing work on the human body. In my view, the increasing important role of bio-power is the product of the disability movement in which the movement activists criticized the notoriety of social barriers that restrict the activities of people with impairments. In Britain, social modellists are of the opinion that disability is the outcome of the erection of social barriers, which results in the confinement of people with impairment within a limited space and preventing them from entering the work place and public domains. Through the social modellists' advocacy, disabling barriers in all areas of social life come into view – in housing, education, employment, transport, cultural and leisure activities, health and welfare services, civil and political rights, and so on. The effort of the social modellists has led to a reveltry and libratory result. Since then more social barriers have been eradicated. In other words, people with impairment enjoy more social spaces and activities. In Hong Kong, similar changes have taken place. Legislation is promising and the establishment of Equal Opportunities Committee brings more hopes for the eradication of social barriers in this regard. Nonetheless, these changes have also lead to more social issues to be concerned with. While people with impairment enjoy more freedom in social life, the possibility of their encountering dangerous and risky circumstances increases. This subject matter would unleash a series of new problems: who are responsible for the people with impairment when they encounter accidents or injury? How to ensure safety for the people with impairment? Generally speaking, the actors in three specific domains are responsible in modern societies. The dominance of the medical model in the domain of rehabilitative science and services renders responsible for the medical practitioners, physiotherapists, and occupational therapists. The rise of welfare states gives an important role to social workers while the advocacy of citizenship, with emphasis on the enhancement of the capability of the people with impairment to be mobile, forces the public transport companies to be responsible for the provision of facilities to people with impairment. It remains a strong social norm thereby family members are regarded as one of the core carers for people with impairment. We, however, should note that the increase in the scope and extent of mobility for the people with impairment entails increase in risk upon them. This requires us to focus on the question as to the response of the various responsible actors towards the increasing risk. In other words, we are concerned with the actors' form of risk management of the people with impairment.

Risk Management of People with Impairment

In the following sections, I will examine the forms of risk management of the people with impairment. The following analysis is based on the interviews I previously conducted. From these cases, we are concerned with the general principle of risk management, that is, the transfer of the actors' responsibilities to the people with impairment. The underlying rationale for this transfer is the promotion of self-care. However, in our view, this transfer leads to the proliferation of disability.

a) *medical practitioners*

Risk factor becomes one of the vital elements relating to impaired bodies. According to medical perspective, people with impairment are treated as a risky group in society. The risks are arising from them include risky behaviours, risk of being attacked by diseases, risk of their bodies being out of control, risk of dying, and so on. For these reasons, the people with impairment are convinced to take measure to exercise suitable monitoring of the management of the risks for themselves. The measure taken is based on a specific conception of body. Martin (1989) has powerfully detailed the fragmentation of the female imaginary body in her study of women's experiences of the federalization of their body processes. Adult body, in this imaginary body view, is understood as a productive system, anything thought of as a failure in production is classified as pathological. Physical impairment in capitalist societies is also regarded as a feature signifying a failure of production, and implicit in this image is the notion of unproductive bodies that must be observed, cared, controlled and mastered through medical intervention. More than this, in the process of federalization, bodies with impairment are fragmented into separate parts and objectified, made to look seemingly separate from the whole body as a person. In other words, a person with impairment is split between an objectified body, which becomes the target of medical, technical intervention, and the various selves, which can only look upon this body as having a detached relation to it. A person with impairment has been cut away from his/her body, leaving the various parts of body with impairment. The person in question is alienated from the process of treating impairment because the medical practitioner steps in to manage the impaired body.

The technological management of the treatment process of physical impairment is based on the distribution of responsibilities for risk management. In this study concerning the risk management of wheel-chair users, we examine the pamphlets of a practical guide for clients and carers to deal with pressure care. In the guide, team approach is advocated. According to the guide, this approach addresses that:

> "Prevention of pressure sores is the business of everybody who takes part in the care of the patient, including the health care team, family member and the patient. Team members have to share the common language, for example, relating to equipment in use or when grading pressure sores. They have to keep open two ways communication so that the progress of the wound is well monitored. They also have to understand the roles, skills and expertise of each team member so that the patient can benefit the most from each profession."(RehAid Centre 2001:12)

We can see that the team approach integrates different expertise but there is a clear distribution of roles for each of the professionals and responsible parties. In the practical guide, it indicates that doctors have been assigned a specific role: "The doctor will have overall responsibility to plan and coordinate patient medical treatments. Specifically, doctors have responsibility to maintain the patient's optimum physiological condition, with particular reference to hydration, nutrition, respiratory function, circulation and infection during treatment. Where appropriate, they should also ensure referral to other professional disciplines in order to employ their specialist knowledge in assessing the need for and planning of appropriate care interventions. Besides treating the underlying diseases, the doctor will carry out wound debridement and operation which are important prerequisites for healing of pressure sores" (RehabAid 2001:23). Clearly, doctors are responsible for ensuring patient's optimum physiological condition. This leaves the other needs for treatment to other professionals, such as the occupational therapist and physiotherapy. In the guide, occupational therapists are responsible for assessing 'a patient's functional abilities, and to recommend and advise on any problems that a patient has in performing those activities of daily living which contribute to the risk of pressure sore formation' (Ibid.: 24). In particular, occupational therapists should 'conduct education program to the patients, caregivers and family members including the following topics: causes of pressure sores, formation of pressure and information' (ibid.:24). The patient and his/her family members turn out to be the responsible parties. However, the patient is not expected to take care of the physiological aspect of his/her impairment, since this part of the body is relegated to the doctor's responsibility domain. Patients are educated to obtain knowledge about 'skin care, pressure reduction, nutrition, mobility and activity, positioning, ulcer treatment program, learning how to perform care. The purpose of education is to facilitate the patient's understanding of the pressure sore problem, encourage participation in decision-making, maximize skills, and promote a healthy lifestyle. Educating patients about risk factors, pressure sore prevention and pressure sore management gives them the power to manage their own care and to oversee the care others provide for them' (Ibid.: 22-23).

This kind of practice is consistent with what Lupton pointed out about the issue of risk and governmentality. She claimed that "people attempt to 'transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality' (Focault 1988:18). In doing so, they seek out and adopt advice from institutional governmental agencies, from experts who have problematized areas of life as pervaded by risk."(1999:88). Experts seem to compartmentalize a patient's body and each part falls into different responsibility domain and these domains are under the surveillance of different expertise. Nevertheless, apart from the physiological aspect of body, there are few domains wherein each involving party could be identified clearly. Patients are encouraged to learn self-help techniques in positioning and mobility, but occupational therapists seem to have similar responsibilities in these respects. I will discuss the role of the occupational therapists in the following section and so far I have shown the extent to which doctors as medical practitioners have drawn a clear line to delimit their scope of responsibilities within the physiological aspect of impairment.

Apart from the study of the discourse prevailing in written form, I will also examine the interaction pattern between doctors and people with impairment and try to find out how much room the doctors leave for the patients to take care of their own responsibilities. The interviewees always mentioned that doctors request them to report their own conditions in each regular medical consultation section. The pattern of patient's reporting in regular medical consultation shows the distribution of responsibility in monitoring physical health between doctors and patients. In each regular medical consultation section, the doctor reminded patients of monitoring their own health. Interviewees also reported that they were forced to prove that they had put effort on keeping their own health. Under this interaction, the patient is located as playing a dominant role in keeping his/her own health while the doctor as the expert offering them assistance in that regard.

The case of Wai (male, about 40 to 50, injured over 20 years, a quadratic injured) shows in the pattern of interaction and the role of doctors in regular consultation sections.

Wai expressed his view in an interview:

Wai: I need to attend regular medical consultation section at orthopedics clinic, twice a year.

Interviewer: Twice a year! What kind of medical examination you had there?

Wai: Nothing, only went there to get medicine home.

Interviewer: Any medical checkup conducted?

Wai: No, nothing of that kind if you didn't request.

Interviewer: Did the doctor ask about your physical condition?

Wai: Sure!

Interviewer: And then, the doctor prescribed some medicine for you?

Wai: There is something, something wrong with me physically, but so long I have been treated the same way.

This case reveals that doctors mainly relied on information obtained from patients' self-reporting. It seems that the patients knew clearly their physiological condition and should be responsible for their own diagnosis. Similar experience has been reported by Kau (male, about 40 to 50, a quadratic injured having an injury history for several years) that doctors regarded regular medical checkup as a waste of time:

Interviewer: In respect to medical aspect, do you need to attend regular medical check up?

Kau: Once half a year.

Interviewer: It is quite a long period of time.

Kau: They don't want to waste the medicine, you know? They might expect to see me again half a year later and then they know I'm still alive. In that case the doctor will give me some medicine.

Interviewer: Ha!

Kau: They don't want to waste resources.

In the case of Sheung (female, about 40, lower part of her body suffering impairment over 20 years), the doctor was criticized as offering little help to the patient:

Interviewer: What do you think of the usefulness of regular medical check up? Is it useful for you?

Sheung: I think it is useless.

Interviewer: Useless?

Sheung: I would like to have more regular medical consultation no matter whether I need it or not. Sometimes I suffered an acute pain but it was not at the time of my regular check up.

Interviewer: Humph!

Sheung: I went to the outpatient clinic when it was not the time for my regular check up. But the doctor told me that there was no way to find out my situation. He even said that he was in no way to find out the cause of my problem even he had my body cut to pieces. Although he prescribed me some medicine that could release my pain, I didn't know what was wrong in my body. There was no improvement in my case after consultation in outpatient clinic.

Interviewer:	Humph!
Sheung:	Well, there is no pain later. It's meaningless to complain about how serious my pain was to the doctor during my regular check up. I'm not sure whether it's right to have medical check up when I need it, or whether regular medical check up is enough.

It was not a surprise for patient Sheung to have heard that the doctor admitted he was unable to cure her pain. When the patient failed to give hints of the cause of the pain in the patient's body, the doctor appeared to take for gained that it was the patient's responsibility to find out the cause. In this situation, the patient did not dare to challenge the authority of the doctor even though she had not received any medical service from the doctor. She just reckoned whether it was necessary for her to attend such medical check up. Then, patient Sheung asserted that the failure to cure her pain was not so much the failure of the doctor as an issue of her decision on attending regular medical check up.

(b) agency responsible for the provision of public transport for the impaired

An interviewee pointed out that 'There are many difficult situations that would annoy a group of disabled in the society. In the case of the transportation facilities, appointment should be made at least a month ago for the service of Rehab Bus. Such arrangements cannot satisfy the daily needs of the disabled such as an emergency consultation or some important appointments. I think this would affect the life of the disabled seriously as long as such a fundamental aspect of transportation cannot be improved,' (Leung, male, aged above 30, quadratic). This interviewee pointed out a fact that public transport remains an issue that give rise to a lot of embarrassments for the people with impairment. Many interviewees who are physically impaired reported their unpleasant experiences in using public transport. It is difficult for wheel-chair user to stop a bus. An interviewee complained that 'Those bus drivers did not know that we could hear them swear. I felt that they didn't really want to help us but they were only obliged to. Sometimes they swore, sometimes they just didn't stop for us. These situations always occur in the route run by a specific bus company. I do not know whether they were in a hurry and couldn't help us. But nine out of ten buses did not stop for me.'

One interviewee mentioned that:

Leung: Take getting on an easy access bus for example, the driver just stops the bus without giving consideration to the exact location of the wheelchair users. Actually the disabled cannot get on such bus easily. They need assistance and more time to get on the bus. Though the driver is willing to help, the passengers on the bus are reluctant to wait. This makes the disabled feel uncomfortable.

Interviewer: Would there be the cases that the bus driver would be unwilling to take on the disabled, as he or she has to be responsible for any accident that should happen to them during the trip?

Interviewer: Such a situation can be avoided if the bus drivers can understand and take care of the disabled through training and education.

Interviewer:	Do you know whether such a situation still goes on now?
Leung:	Such a situation often takes place up to now. In the case of taking taxi, some drivers would not help because they still assume that the disabled can bend their wheelchairs and put them into the car. The taxi drivers would still have some old mentality that the disabled would transmit bacteria to them.

Such a reaction of the taxi driver towards people with impairment is not unusual. Their reluctance may come from misunderstanding, and in some cases it comes from self-protection. As an interviewee reported that 'It was because those drivers might think they would be injured easily when they move the heavy gears into their car such as the wheelchairs of the disabled. They always use such an excuse to refuse to give help, and that's their usual practice.' In view of the social barriers against their participation in social life, many people with impairments would formulate their own living strategies in an attempt to avoid embarrassing situation. A wheelchair user admitted in the interview that he avoided going to places where public transport was inaccessible:

Leung:	For example, I may not be able to go to some places because not every route has bus with super low floor. If I want to go to such places, I have to plan how to get there and information must be gathered beforehand. There are lots of places I have not visited before. I have to consider lots of things before I decide to visit somewhere not well known to me. Thus, what I mean is that, if there is Rehab Bus, some obstacles would be removed though I still have to cope with other problems.
Interviewer:	You mean the Rehab Bus service already has super low floor. Then how about other transportation services? For example, there are certain problems.
Leung:	The platform sometimes doesn't work.

Interviewer: What do you mean by the platform doesn't work?

Leung: Not all the platforms are automatic. Some of them are semi-automatic and I can do nothing if the platform cannot be lowered.

Interviewer: Do you mean that the platform cannot be lowered to the ground to enable your wheelchair to get on the bus?

Leung: Yes! In case the driver is not willing to open the platform then you have no chance to get on the bus.

Interviewer: Did such situation occur before?

Leung: Yes! It happened a lot.

Interviewer: I know there were such cases.

Leung: Sometimes even the driver was really eager to help, but the platform practically couldn't be put onto the ground. I was really frustrated and in a hurry. A normal person can take a bus whenever he wants, but I always had to wait for several hours. It depends a lot on luck.

Interviewer: Sometimes you had to wait for a long period of time?

Leung: Yes! Sometimes you have to see if the driver is willing to help. It seems to me there is still a lot to be done to assist the disabled as there are obstacles still everywhere. For example, some of the MTR stations do not have elevators for the disabled

Interviewer: No elevators?

Leung: No! Sometimes we had to use something we call 'monster machine' (怪獸車 its proper name is wheelchair lift) to help us to get on the station platform. I had a job in TST before but sometimes even the 'monster machine' couldn't help me to get on the station platform in TsimShaTsui, so I had to wait for a long time.

Interviewer: Why? Was it because your wheelchairs are very heavy?

Leung: Some of the wheelchairs are very heavy. But mine is ok, it was because the 'monster machine' didn't work.

Interviewer: Was it because the 'monster machine' was incapable of carrying the weight of a wheelchair plus a person?

Leung: That's right!

Interviewer: That means sometimes the 'monster machine' does not work and cannot move?

Leung: Yes! Anyway, we had to wait for a long time as it took some time for the staff of the MTR to take us out of the platform. Sometimes it took more than an hour. Though there are some 'walky-talkies' in the station to let us know their staffs were coming to take us out, we still felt insecure, as we had to wait there for more than an hour before they came.

Interviewer: Did it take so long?

Leung: Yes! But I'm not sure whether I had informed them. It may be my problem, I was unable to inform the security.

Interviewer: That means those staffs did not come immediately?

Leung: Those staffs did admit that they could not come to help immediately, as they have to make some arrangements among themselves first. I think our right (disabled) is regarded as secondary. It was important for me to have access to transportation easily, especially when I was in a hurry. But others gave me the impression that they didn't care for our situation and just always let us wait. So far the situation has not changed much though there has been some improvement.

Interviewer: Instead of the improvements in the transportation facilities, you still feel that the disabled are regarded as second-class passengers? And the right of the disabled is neglected?

Leung: I don't think that our right is neglected. It is because their staffs have to make adjustments and arrangements first, so that the process of helping us will be slowed down. What I feel is that there is lack of respect. People would say you could simply go down there to take a bus if you didn't want to wait, but we couldn't.

In fact, it was necessary for this interviewee to avoid going somewhere. But in the interview, we can see that the interviewee did not blame the 'monster machine' even if it was not capable of carrying heavy wheelchair. He seemed to be satisfied with his own relatively light wheelchair. Buying a lightweight wheelchair is certainly an individual solution of the problem of going upstairs.

He did not choose blaming the poor performance of the 'monster machine'. It appears that a public issue, that is, the provision of a powerful machine to ensure mobility for each citizen, has turned out to be an individual one. Similarly, when he encountered difficulties in getting away from the railway station platform, he doubted if it was the problem of communication rather than the railway station staff members' insufficient attention given to the people with impairment. In his mind, personal inadequacy is always the first reason for their inconvenience. In fact, he complained that their citizen status had been regarded as secondary. But when the interviewer attempted to confirm his view in this respect, he answered in the affirmative. He admitted that 'there is a lack of respect' in his case. When the rights of people with impairment have been neglected, it becomes a public and political issue. The lack of suitable facilities for people with impairment signifies the existence of a non-social inclusive society, and this is also a public and political issue. However, lack of respect just relates to social norms and the whole issue is transformed into a social one in nature. Moreover, attributing the reason for their own inconvenience to personal adequacy further transforms the nature of social issue into a personal issue. In other words, if he felt insecure while waiting at the railway station for the staff members to come to help him to leave, the risk and the bad feeling he had became a personal issue. Translating public issues into personal issues discourages discussion over the exclusiveness of built environment. The cost of bearing risks in turn becomes the burden of the people with impairment. We can in other cases see how people with impairment deal with the risks inherent in our built environment.

Interviewer: What kinds of transportation do you normally use when you go out?

Keung: My friend would take me there if I have to go to somewhere far away. But I would take a taxi if the destination is near my home.

Interviewer: How about other transportation services, such as bus and MTR?

Keung: Relatively speaking, I seldom use them.

Interviewer: Why?

Keung: I need someone to accompany me if I decide to take a bus or MTR because the gap between the platform and the train is quite wide.

Interviewer: Do you refer to MTR?

Keung: Yes. In that case, I am afraid of taking an MTR, especially with the wheelchair.

Interviewer: Did you just start using wheelchair recently?

Keung: Yes.

Interviewer: You are still unfamiliar with it, right?

Keung: Right.

Interviewer: How about taking bus, do they have super low floor now?

Keung: Though they are called super low floor, there is no slope. That means it is equal to no difference.

Interviewer: Which number of bus does not have super low floor or that cannot be pulled down onto the ground?

Keung: Such a thing often occurred in No. 104 bus. It is because I have to travel to Hong Kong Island quite often recently. Once I tried to get on the bus, but the super low floor couldn't be pulled down onto the ground. Fortunately I had a speller with me and I asked my son to use it to make it work. Finally I was able to get on the bus.

Interviewer:	It has to be fixed by hand?
Keung:	Yes! Another time I was waiting for the bus in Admiralty at around 8 pm. I had waited for a bus with super low floor for an hour and 45 minutes there. Most of the buses do not have super low floor during that period of time. Actually they have time limit.
Interviewer:	That means in a certain period of time, there will be no bus with super low floor? In that case you have to wait for a long time for it?
Keung:	That's right!
Interviewer:	It's strange!
Keung:	Yes! But we did not know the situation and just kept waiting there. I asked a driver about it and he told me buses with super low floor would be available some time later. No wonder that we had to wait for several hours.
Interviewer:	You have waited for an hour and 45 minutes.
Keung:	Yes.
Interviewer:	I had a talk with Leung last time. He told me that once he had waited for routes number 26 bus in TsimShaTsui. Four or five buses passed by, but none of them had super low floor. This situation lasted for more than 40 minutes. It was at daytime. But he had to wait for more than an hour. I really think that he should lodge a complaint with the bus company by phone about the situation.
Keung:	Thus, the bus company has not told us about such inconvenience.
Interviewer:	But according to their advertisements or announcement, they plan to continue to purchase this kind of buses. Your experience shows that, firstly, the frequency of such kind of buses is very low; secondly, the super low floor doesn't work. On the other hand, the gap between the train and the platform of MTR and KCR is very wide. Have you ever complained about these things? And have you ever received any response? Or have you found any improvements in that regard?
Keung:	I have not seen any improvement yet. But I have been treated nicely once. That was on my way to Shenzhen. They arranged some slopes for us.
Interviewer:	Where did you refer?
Keung:	The Kowloon Tong KCR Station. Pretty good.

Interviewer: Did you inform the station beforehand?

Keung: Yes!

Clearly the interviewee did not put too much blame on the effects of social exclusion arising from the exclusive built environment. He bore the cost of finding somebody to go out with him so as to handle any emergency arising from the non-wheelchair user friendly transport. He even took the risk of using equipment to fix the facility for wheelchair user. There has been no clear social consensus about who should be responsible for compensation in case the interviewee is injured when fixing the automatic ramp. The interviewee was certainly willing to deal with the risk of being injured. However, to other people with impairment who either know nothing about fixing the ramp or is reluctant to do the job, geographical mobility becomes a difficult task. They are then barred from enjoying mobility and then the chances of social participation. This sort of invisible barrier comes not only from limited provision of buses with ramp and super low floor but also from the ambivalence in attitude towards the responsibility of risk sharing.

(c) *People responsible for managing the living areas where people with impairment live*

Modern societies seem to be less suitable for people with impairment. Heavy traffic and dense living arrangement prevent people with impairment from getting more space for mobility. We can distinguish between 'inner' and 'outer' social life to see how people with impairment deal with their daily life. Certainly people with impairment need assistance especially when the living arrangement in modern societies is largely exclusive. Built environment is designed for the blest and thereby somewhat wheelchair unfriendly. In order to live a pleasant social life, many people with impairment are reluctant to go shopping or to participate in recreational activities. However, the inner built environment is not friendly towards people with impairment. Hence, they need assistance even if they are living within their own accommodation units. Owing to the dominant traditional norms that family members remain the principle carers of people with impairment, assistance for handling daily life is still mainly from family. This is particularly true with the case of emergency. An interviewee, like many other people with impairment, relied on the support of his family members.

Interviewer: If you suddenly feel uncomfortable during the non-working hours of the clinic, they do not have any emergency service for you. Then what would you do under such circumstances?

Chi: It all depends on the decision of my family.

Interviewer: You have to ask your family first?

Chi: Yes. Or I will ask my close friends for help.

Interviewer: How about dialing 999 for emergency car?

Chi: It is difficult to define whether the situation is emergent or not. Thus, I always delayed going to see the doctor until the next day even I ran a high fever. Then my sickness might get worse.

Interviewer: Did you mean that you were not sure if people would accept your case as emergency? So you prefer asking your family or close friends for help?

Chi: You are right!

However, people with impairment have a strong urge for being independent. They prefer leading a life of mobility with a higher degree. They want to enjoy life in the form of independent living. This tendency was revealed in an interview. A man with impairment proclaimed that 'I am living in X X X with my family. My younger sister and elder brother have been married and have moved away from home. Normally my living, such as bathing, is assisted by home helper. My mum would help me in my daily life too. But I help myself most.'

Being independent is a very important strategy for a person with impairment who tries to build up his/her identity. People with impairment find it difficult to handle the tasks arising from their daily life. This would often give them a sense of powerlessness. On the contrary, being able to handle housework and self-care signifies a person with independence. One of my interviewee has showed his strong desire to be independent.

Leung: It's quite difficult. For example, if it is really hot or I make myself dirty accidentally, I may want to have a bath more than once a day. Though it may be difficult to ask others for help but I would try. Or I would try to take a bath by myself but I do not have the ability.

Interviewer: No one has enough physical strength to do so?

Leung: No! It is like a battle for us to take a bath. And it is also impossible for us to have the same feeling with others helping us. Maybe we just have shower on ourselves but we can't do it without other people's help.

Interviewer: Normally, whom would you ask for help?

Leung: I would ask my close friend to help me. Maybe they have helped me before, and then I would like to ask them again..

Interviewer: You just now said that the home-helper would help you with your bathing, then how about other aspects of you everyday-life?

Leung: I am pretty independent. Apart from something that I am really unable to do, such as bathing, I would try to do whatever I can. For example, I feel free to have my breakfast and meal myself. I love freedom and do whatever I like, such as when and where to eat. I do not like to be restricted. With the exception of taking bath, not many things are really difficult to me.

Since social life becomes privatized, many facilities have been built within the accommodation unit of people with impairment. They obtain help from physiotherapists and occupational therapists to renovate the interior design of their accommodation units. Risk seems to be reduced in this respect. However, the outer social world remains an unpleasant place to go for people with impairment. Unpleasant experience is not only from the wheel-chair 'unfriendly' built environment but also from the reaction of the public. Social exclusion arises from discriminatory attitudes of ordinary people against people with impairment. But we argue that it is the specific form of risk perception and risk aversion that leads to more unpleasant experiences. Through interviewees, I found that security guards and policemen, who are people more likely to be involved in the social life of the people with impairment, tend to be risk-aversive, thus creating more invisible barriers against the mobility and social participation of people with impairment. This is shown in a case of a wheelchair user.

Leung: It is my freedom to go home late at night. But once the elevator did not work at around 12 pm and I had to call the police. I couldn't go home without the elevator. Finally I asked the security guards of the estate for help.

Interviewer: The police didn't come?

Leung: The security guards refused to help, as they were not in a position to be responsible for any accident.

Interviewer: Were they afraid of hurting you?

Leung: They were afraid of hurting my vertebra.

Interviewer: Were they afraid of hurting you or themselves?

Leung: Both. What could I do at 12 pm if they were not willing to help? This is a long-standing problem. The security guards asked me to call the police and I did. I remembered that two years ago a similar event had taken place in which I was really hurt. The lift was down and a police came. He explained to me that he had to call three more colleagues to come to help me. But this was not his responsibility. He told me not to go out at late night. I told him that I was just off from work. I really didn't know what I should do and what I shouldn't do. We are disabled and we cannot go home without lift, thus we call for help. But what they thought to help me would cause risks.

Interviewer: You think that they were concerned with your safety?

Leung: I should say that this is a serious problem, as I cannot go home. But the result was that both the police and security guards did not offer me help and I had to hang about in the street.

Interviewer: Did the police really go away?

Leung: Yes! He said that nobody could help me as I returned so late. All I could do was to hang about in the street. I also faced lots of similar problems in my job, which I really cannot understand. We always need others' help because we are disabled. We have freedom to go out at night. This is not just my problem, but also the problem to all the disabled. I have many friends and classmates who also had met such problems before. I really cannot understand why it would be like that.

Interviewer: Is it the same problem, i.e. no elevator to go home?

Leung: Exactly!

Interviewer: Do you think that they were afraid of hurting you or them, thus, they did not want to bear the risk of help?

Leung: Yes! They said that they were not in a position to be responsible for my safety. Their excuse was that my wheelchair was too heavy. I can accept that if people do not want to help, but please say it out directly. This really hurt me very much. I'm sure this situation will remain unchanged in the coming 10 or 20 years.

Interviewer: Do you think that such events would go on to happen? In this event, how do you look at the interrelationship between the safety of the disabled and the services of the professionals (Police)?

Leung: I really don't know whether we should solve the problem I just mentioned. I also don't know if I should tell the social workers about it. I wonder if they would help us to solve the problem.

People tend to be risk averse when faced with uncertainty. The policemen and the security guards were reluctant to help the interviewee, not because of their lack of sympathy for the people with impairment, but because of the ambiguity in bearing the responsibility for dealing with risk. Although they are concerned with the well being of citizens, there are few guidelines for them to handle issues arising from people with impairment. Using wheelchair appears to be a private matter and in public domain the responsible parties would not be prepared to offer assistance. Without clear guidelines, the policemen and security guards had no means to assess the seriousness of the risk arising from helping the interviewee. Because of the lack of information about potential harms that might incur upon people with impairment, they chose risk avoidance. This issue reveals that the lack of consideration for risk perception, risk assessment and risk handling within the public institutions, people with impairment encounter more social barriers in their daily life. Given that people with impairment are more likely to be powerless and helpless in difficult situation, they tend to stay at their inner world. In fact, many average people expect them to be so. People like the policemen and security guards would think, staying at home or coming home earlier seems to be more suitable for people with impairment. They understand that the people with impairment are vulnerable to any threats, and they perceive threats as having serious consequences that they are unable to share the responsibility. Therefore, they prefer less geographical mobility for the people with impairment to more social participation. Their calculation is not out of discriminations, but out of the rational calculation of risk avoidance. They might think less mobility was good to the people with impairment. The benefit of their staying at home is regarded as the right action that outweighs the costs of being less mobile. However, they are not aware of its result that the people with impairment have thus been curtailed of their chance to enjoy citizenship, the chance to enjoy freedom and independence. We can see that modern societies educate people to be rational and emotion-free and the costs of this education are somewhat borne by the people with impairment as a whole. The widespread utilitarian philosophy promotes the idea that rational being must be 'warm-blooded, passionate, inherently social beings though we think we are, humans are presented in this context as hedonic calculators calmly seeking to pursue private interests. We are said to be risk-aversive, but, alas, so inefficient in handling information that we are unintentional risk-takers; basically we are fools' (Douglas 1992:13). Apparently the policemen and security guards did not want to act as fools, so, in order to be emotion-free and rational, they should act in a risk-aversive way.

Apart from risk avoidance, professionals are also employed to deal with the demands from the people with impairments. Technology however does bring many benefits to people with impairments. The dominance of professionals prevails and the people with impairments are unable to challenge. This is shown in a case of the design for ramps.

Interviewer: Now you are living in public housing. I find there are some modifications in your apartment.

Keung: Yes, there are changes in many aspects. The corridor and the entry of my apartment are not at the same level. The corridor is a little bit lower than the entry. So I needed a ramp at the entry for my wheelchair to pass through. However, my neighbour showed their discontent about this change because this would also affect the entry of their home. That is why the entry of my apartment has shifted to other side.

Interviewer: Are there any changes in your washroom?

Keung: Yes, there are. There is also change in the balcony.

Interviewer: Who made these changes? You or the Housing Department?

Keung: I requested the Housing Department to make the changes, after I had received the services of physiotherapy.

Interviewer: With the recommendation of doctor and physiotherapist?

Keung: At the beginning, the Housing Department only gave me a tin plate. Each time when I went out, I had to put it over my entrance and the corridor. After I got down to the corridor, I had to put it back. However, the tin-plate blended in the middle later.

Interviewer: Is it not solid enough?

Keung: Right! Then, I got a recommendation letter from the physiotherapist in the hospital.

Interviewer: Why did the Housing Department reject your demand of making a concrete ramp for you? Did the Housing Department give you the reason?

Keung: They replied that there was no such precedence.

Interviewer: Because they feared they had to bear the responsibility?

Keung: Yes!

Interviewer: Did the Department make a concrete ramp at the entrance of your washroom?

Keung: No! The Department just gave me another tin plate.

Interviewer: Just like the case of your balcony, the Department solved your problems by giving you tin plates.

Keung: Yes! I thought that I had to move the tin plates day in and day out all my life. I could do nothing after all my family members had gone to work. I had explained the situation in detail to the senior staff, who really could make decision.

Interviewer: How much time did you spend in negotiating with the Department?

Keung: A month or so. They changed their minds when the tin plates really didn't work.

Interviewer: Are there any problems in this housing estate?

Keung: I cannot get into the lobby of my block. The ramp is so steep that I cannot move my wheelchair onto it.

Interviewer: You mean the ramp beside the stairs?

Keung: Yes! But it has improved in recent years. It is not so steep now.

Interviewer: It must be hard for you and it must have taken a lot of your energy when you tried to get into the lobby in the past.

Keung: Yes! At that time, I was still strong enough. However, I am not so physically strong now.

Interviewer: Was it hard for you to bargain with the Department?

Keung: Yes! It was very difficult to make any changes by yourself alone. You must get the support from organizations. I changed two ramps at the entries of the estate with the supporting letter from organizations. I had asked for changes for two year, i. e. since 1998, with complaint letters. But it didn't work even after the housing manager was involved. New ramps were installed only after the Direction Association for the Physically Handicapped had sent a letter to support me.

Interviewer: Is it true that the Housing Department or government would not consider the individual opinions of the wheelchair users?

Keung: They claimed that they considered the opinions and everything was under handling.

Interviewer: Would the responses from the departments be speeded up with the intervention of the Direction Association for the Physically Handicapped or the physiotherapist?

Keung: Yes! The responses were speeded up. I have experience that the Department rejected to make any change until I sought help from

	Equal Opportunities Committee.
Interviewer:	Then what happened?
Keung:	The ramps at the entry of the lift were too steep for me to push the wheelchair into the lift. My wheelchair is not the electric one. The Department rejected to change the ramps, instead it installed two handrails at the entry. However, the handrails didn't work.
Interviewer:	There are engineers working in the Department!
Keung:	The Department claimed that their engineers were professional.
Interviewer:	It seems that the Department really did not know what you needed. Has the Department ever collected your opinions?
Keung:	No!

Summary

Living in modern societies where independence is appraised as the essential capacity of human beings, each individual knows personal performative capacities are at a premium and should make them visible to others. This is the strategy for individuals to gain their proper position of citizenship in modern societies. Wheelchair users, just like any other people with 'visible' impairment, find it more demanding for them to accomplish this since the visibility of their impairment under public gaze has already put them in a less equal social position. With the common belief that people with impairment are vulnerable to modern urban life, average people would categorize them as the 'Other', showing them sympathy or discriminating them. In this chapter, I attempt to illustrate that in three different domains, namely medical setting, public setting and the private home, people with impairment should live differently and negotiate their subjectivity. I focus on the way the interaction pattern between the average people and the people with impairment in respect of risk management. We have come to the argument that in Hong Kong where individualism prevails and the lack of the sense of community is prominent, the bodies of the people with impairment have been marked by a script that individuals should be responsible for the management of the risks being encountered in their daily life. Therefore, people with impairment should learn how to exercise self-care and be responsible for any problems arising from their daily life.

In the medical setting, despite the dominance of medical explanation and knowledge about the causes of physical impairment, the doctors seem to take self-reporting as the most suitable method of diagnosis. The authoritative medical scripts are out of the hands of the people with impairment and so it is not easy for them to report clearly their subjective feelings and physical state to the doctors. While the self-help guideline stresses that the inner bodily world of the patients is under the responsibility domain of medical practitioners and that part of the body has been cut off from the intellect of the patients, the doctors request the patients to report the state of the inner part. In a case, the doctor even admitted that he had no solution to relieve the interviewee's pain. This sounds contradictory and ironic. But this was the personal experience of the people with impairment in the medical setting. People with impairment have little power to negotiate with the authoritative medical practitioners and eventually doubt the effectiveness of regular medical checkup. When the issue is understood as a personal decision on whether one is to attend regular medical checkup, people with impairment have an idea that on the one hand one is responsible for one's body, and on the other one should bear the cost incurring from the risk of not attending regular medical checkup.

The issue of risk comes into view in the everyday life of people with visible impairments. This is a common issue in the use of public transport. Wheelchair needs more space and the wheelchair users need more time to get on the bus. There arises a question as to the optimal time and space for the people with impairment to use the public transport. People may think it time-consuming and not fit the temporality of modern societies. Our interviewee seemed to be unable to counteract this idea and therefore they preferred to wait for a long time for a bus with a ramp. They seldom made complaints. Clearly the provision of buses with automatic ramp seems to be an improvement in the promotion of inclusive society. However, there is an issue in this respect.

There is little clear guideline for the bus driver to comprehend their responsibility once the ramp does not work. Who should fix the mechanical device? One interviewee thought of this as his own responsibility, and took out his speller to fix it. He also asked his son to accompany him to get on a bus. Similarly, one interviewee did not complain of the poor performance of the wheelchair lift, on the contrary he bought a lightweight wheelchair so as to adapt to the built environment. Their reaction manifests that they take the provision of devices to ensure their own mobility as their own responsibility. They seem to be willing to bear the costs of taking risks arising from being mobility. One took the financial risk of buying expensive lightweight wheelchairs and the other took the risk of possibly being injured in fixing the automatic ramp of the public bus by him.

While people with impairments show strong willingness to take risk, the people who are supposedly responsible for protecting and promoting the well being of citizens show an opposite tendency. As has been argued, it is perhaps because of the lack of discussion on the exclusive nature of the built environment in Hong Kong, public safety agencies have few guidelines for them to follow in the case of offering assistance to people with impairments. Taxi drivers worry that offering help in lifting wheelchair would bring them injury and therefore are reluctant to take such risks. Policemen have the same worry and back out even if they found a wheelchair user unable to go home when elevator was out of order. Security guards attempted to shift the burden to the police in order to avoid taking any risks. This social attitude has become a barrier against the effort of people with impairment to try to be geographically mobile. This kind of attitude not only discourages people with impairment from going out to realize their rights to social participation, but also helps people with impairments foster the idea that they should confine themselves within their private homes. When personal living space is designated as the most safe and suitable place for people with impairments to stay, and the occupational therapists and physiotherapists put much effort on improving the interior design for people with impairments, disability is created and reproduced. Unless the built environment has been designed in an inclusive way and the public is willing to share the responsibility of taking risks, people with impairments will remain trapped in their private world. This is really a situation in which physical impairment is translated into disability.

- End -

Chapter 4

Negotiations of a Disabled Life

Materialist perspectives on disability, promoted by Finkelstein (1980) and Mike Oliver (1990), attempt to associate disability with the capitalist relationship of production. Such a view suggests that many people with impairments are unable to sell their labour power and are thus categorized as non-productive and dependents. Further dependency of impaired people is created on account of the existence of barriers in the employment, education, welfare services, housing, transport, cultural and leisure domains. In short, disability is said to be the outcomes of social relationship at specific historical junctions, with a strong link to economic structure. Following these general theoretical tenets, social modellists see a focus on the material and economic roots of disability. However, as Thomas (2002) argued, 'disability studies in Britain has been enriched by the growing presence of perspectives and issues that have challenged the materialist prioritization of the economic roots of disability and the contemporary operation structural barriers in the wider social environment' (2002:48). Basically, the issues of signification in the debate revolve around the importance of cultural processes and discourses in the generation of disability and disablism.

Shakespeare is critical of the social model because, in his view, 'a determinist view, [materialism] does not give much explanatory space of autonomy to the realm of culture and meaning' (Shakespeare 1997:224). Corker also argued that 'because human agency is lost in the materialism of the social model and because discourse is seen to be a side-effect of social structure, neither can be the focus for social change' (Corker 1998:39).

When bringing the human agency back into the disability studies, the studies of disability start to put the focus on the relevance and nature of impairment. This view has certainly clashed with the social modellists' view that the personal experience of living with impairment is not the major concern of disability studies, and that intellectual and political efforts should be concentrated on the examination and investigation of the wider social causes of disability. One strand of this line of thought came from feminist writers like Morris (1996) who saw the relegation of impairment to the domain of insignificant as problematic. She argued that 'there was a concern amongst some disabled women that the way our experience was being politicized didn't leave much room for acknowledging our experience of our bodies; that too often there wasn't room for talking about the experience of impairment, that a lot of us feel pressurized into just focusing on social barriers' (Morris 1996:13). Her view is consistent with what many feminists have found out of women's gendered specific experience of their embodiment. Martin (1989) in her study has come to the conclusion that while medical understanding promotes the view of the body as mechanical, objective and fragmented, many women did give phenomenological accounts of their bodies, that is formed on the basis of women's own experiences of the lived body as it blended with more informal advice and the wisdom passed on them by other women. Drawing on these insights from feminists writers, some social constructionist feminists brought to life again the feminist slogan 'personal is political' in the field of disability studies.

As I have argued in Chapter 2, Thomas (1999) has offered a general perspective that serves as our theoretical guideline in understanding and tackling the personal experience of impaired people. The aim of her approach to the psycho-emotional dimensions of disablism is to explore the extent to which social imposition of restrictions of activity on people with impairments shape personal identity, subjectivity or the landscapes of their interior worlds. The focus of this approach include a concern for (a) what the impaired people do, (b) how they act (are prevented from doing and acting) as disabled people, (c) who they are (are prevented from being), and how they feel and think about themselves. Her view is based on the idea that 'psycho-emotional impairment effects are significant, however, since they play a part in many disabled people's lives, and have to be understood in social and not just biological terms' (Thomas 1999:47). Apart from restrictions of activity that have impacts on the scope and range of everyday activities of impaired people, restrictions erected within impaired people also place limits on their psycho-emotional well being. As Barnes *et al.* summarized her idea in the way that the recognition and theorization of the psycho-emotional dimensions of disability is, "namely, those disablist practices that undermine the psychological and emotional well-being of people with impairments – what disabled activists have referred to as 'internalised oppression' (2002:10).

In Thomas's view, since disabled people are not simply passive recipients or victims of disablism, in reaction to the outer and inner restrictions, disabled people exercise agency and resist. This chapter is to examine the extent to which restrictions affect the psycho-emotional well-being, and to see how the impaired people resist disablism.

Experiencing the psycho-emotional dimensions of disablism

In the 1970s and 1980s, many feminist writers, in the wake of the awareness of the absence of the personal voices of impaired people, invoked 'experience' in order to realize their political slogans of 'bringing in of the personal'. In the

1990s, Thomas followed suit and presented the first-person accounts to illustrate what she meant by the psycho-emotional dimensions of disability. Few studies conducted in Hong Kong designed to reveal such an aspect of disability and we have thus little information as a means to understand the lived experience of the impaired people. Here I present the accounts of the impaired people in order to show that disability in Hong Kong has led to practical and personal consequences of living with impairments. In particular, the detailed account of the day-to-day life of individuals with impairment tells us an enormous amount of experiences of disability from which we could explore if there is any resistance initiated by the impaired people to fight for a respectable and dignified way of being. As Thomas pointed out, 'the study of experience (our own and that of others) is a very powerful way (and sometimes the only way) to understand the world – a precondition for changing it' (1999:79). In the following accounts, I adopt Thomas's analytical distinction between 'the experiences of restrictions of activity, or limitations to social action, which are a result of disability (understood in its social relational sense); the experiences of the psycho-emotional consequences of disablism, or limitations to social being; and the experiences of living with impairment and impairment effects, which include both restrictions of activity and psycho-emotional consequences' (Ibid.: 80).

Case 1

Fong, female, is about 45 of age, with impairments in the lower part of her body. As she is a poliomyelitis, she has muscle weakness on her upper limbs, and thus cannot propel her wheelchair properly. She can only manage to propel her wheelchair for a short distance on a flatten place. Hence, she has always stayed at home. She was not able to work and unfortunately her husband died five months before our interview. Most of the time, she had been taken care of by her husband who also had his lower part impaired. They liked to have a walk around Shatin. In the past, Fong's husband propelled his wheelchair ahead, which at the same time pushed Fong's wheelchair forward. That was the way they had a walk together. But their life was not easy. Her husband managed to do every bit and piece of their housework. To the non-disabled, their life was full of dangers.

Interviewer: Could you tell me more?

Fong: For reaching high place, my husband (a wheelchair user) would open a dinner table and put a wheelchair and tools on it. Then he would push the table to the right place. He set on the table and pushed up his body on the wheelchair. So that he could reach the high place and finished his work. He usually said that don't rely on others, if we could handle the problem. This was our character. However, he became older and weakened. Once, he fell down. I thought we needed home help service. But he didn't like home-helper. Because we had to wait for them. And the home-helpers were calculative, but they work at most three quarters in an hour section. The home-helper would come only two times in a month. What the service could do was very little. My husband had an orthopedic surgery and had a metal in his body for supporting his spinal column. So he must not fell down again.

I told him that it was not a big deal for seeking help. Later, I needed help for escorting me to Tai Wai to visit doctor. So the Social Welfare Department has started home-help service for me. The home-helper is responsible for cleaning up the things and the work of high place. I would finish the work of lower place by myself.

Fong: So the disabled people couldn't take care of themselves.

The design of the public housing estate imposed a great impact on the mobility of them. Fong had moved several times in an attempt to find a place with accessibility. However, she was upset by the estate design. She wanted to have a flat where two lifts were available, since she could have a lift when the other was out of service.

Fong had encountered more difficulties in everyday life right after she got to know that her husband had cancer. For the sake of taking care of her dying husband who was admitted to hospital at Princes of Wales Hospital, she moved to Cheshire Home. However, she experienced being 'evicted' that was skillfully tried by the medical practitioners there.

Interviewer: Did you ever contact SWD, or social welfare organization for help at that time, or did you ever have a thought of asking for their help?

Fong: No. Because I knew it was useless, I was very unhappy when I got to be Chesire Home. I had been forced out right from the start.

Interviewer: What do you mean?

Fong: I may live there last for two months, but after one month and a half, they forced me out.

Interviewer: That means they didn't want you to stay long.

Fong: No. I tell them about my husband's situation at that time in hope that they would consider our situation. I told them that if I had other options I would not be staying there, for I was not a dependent person. If I were able to leave, I would leave. They also forced my husband, and always called for meeting. Ten or more women (Q: to have meeting with you), ten and more people surrounded me, asking my situation, my husband's situation. They said my husband's situation was not my excuse to stay there. I argued that I was not unwilling to go away, but that I should wait until the situation became stable.

The meeting took place at the site that seemed to be where medical practitioners and social workers were practicing their professions. Fong had little to resist the dominance of the professionals and just had to change her mind. She started thinking that her staying was not the optional choice. She had attempted to resist but failed.

Fong: Due to the unstable health condition of my husband, I hoped that they could allow me to stay a bit longer. I said you promised to let me stay for two months, and I was still new here, while other housemate didn't have to have meetings, why did I need so many meetings, with so many of you?

Interviewer: Who were those women?

Fong: Social workers, professional physicians, physiotherapists, managers etc (Q: doctors), doctors, yeah, all of them. Sitting there, asking me to speak out and solve the problem by ourselves. I asked them to consider what inconvenience I would face when I went back home. They argued that the home-helper could handle the household work. For the night, a safety bell would be awakened in case of emergency. Therefore they didn't understand me. I was basically not O.K. Even I could go home by myself. I could open the door and windows by myself but I only could use the microwave oven to boil water but I dare not use the boiling pot to heat water up. When my husband went out to work, I only dared to use the microwave oven for cooking when he was in hospital during the past years. In 1985 he was in hospital, I just brought lunch box. Afterwards, I tried to cook some western foods. At night I would use the oven to heat it up, so the facility was suitable for me. You asked me to buy the ingredient and cooked. The whole process was so complicated that it simply was beyond my ability. They asked me to seek help from the home-helper. The home-helper couldn't stand by my side all the time. Do you agree? The helper only could bring me some food in daytime and in the evening respectively, but they even didn't like to do it in weekends. Do you think so?

Interviewer: Was he in Cheshire Home? How long did you have a meeting?

Fong: ...very frequent.

Interviewer: Very frequent, once per month?

Fong: More than that, about ten or eight days they would call for a meeting. The meeting had so much pressure on me and I couldn't stand it.

Interviewer: Were you asked the same questions in every time, under the same situation?

Fong: Yeah, they asked the same questions but they did not really understand me. A social worker had talked to me about these things.

Interviewer: What did he say?

Fong: In the morning on 2nd of March 2001, my husband passed away. At 4 pm, he had passed away and the social worker came, and I told him the bad news. He asked me to go to see him, then I followed him. He forced me to leave, accusing me of "consulting my own convenience". He said I stayed there was for my own benefit so that I could go to New Town Plaza more conveniently for social gathering and I shouldn't stay there any longer. The death of my husband was not an excuse. He told me so. I begged to have a little time to spare, for I had to handle my husband's affair. Then he wanted me to leave the next day. I asked him to give me more time, perhaps two weeks' time, then I would have got everything settled. Where did I go? How did I go back to my home? But he refused to let me stay.

Interviewer: They didn't give you even two more weeks?

Fong: No. He accused me of only consulting my own convenience, or being fond of joining people in New Town Plaza. And he said he had seen me going to New Town Plaza. I said I went there to visit my husband. I said I only asked my housemate to buy the daily necessity for me, I had no time left to go there, since I knew my husband's situation. It would be very tiring for me to go there. Going to Tseng Kwan O, to Shatin daily (Q: It is a long way), very tiresome. Right? I only wanted to stay with him as long as possible. Afterwards I asked to transfer him to Bradbury Hospice. I said to the doctor that he had only several weeks left. Then I asked to cross pass the district, back to Bradbury Hospice, so that I could take care of him more easily. On the one hand it would save money on traffic. It cost almost a hundred for a full turn. And it was time consuming too. (half an hour) It is more convenient to be so, so I asked the doctors of Bradbury Hospice whether he could be transferred there. I said I was very tired. I wanted to stay with my husband for a longer time. The doctor said: as you know your husband has only several weeks left, and it would be very difficult to cross the districts, so he could only try his luck. He also said that they had to ask for my husbands' approval too. My husband then told the doctors to follow my words. In fact he really liked to go back to Shatin, his family was in Shatin. Finally, he said there was no way in helping me. Then I asked for help from the Catholic sister in Tai Hau Wan. We used to live there when we were young for many years. During the time in hospital, she was the Head Nurse, some of them were doctors, so I asked for their help. At long last we were lucky to have obtain the transfer. My husband really wanted to go back to Shatin, but he passed away the day after he was back, but anyway he had his will fulfilled. I think I am grateful, as I was there when he was gone, then at last (Q: he refused to give you two weeks), that makes me so depressed. They were forcing me out. Since the time I was there, my life had been really tough. On one hand my husband was seriously ill, and on the other, they forced me out, always have meeting with me, discussing that useless stuff only. They didn't do what I ask to do. They had told me that even my husband had been ok, we still would ask for staying in the hostel so that we could add our names on to the list until the day we got older. However, he did not get help.

She made complaints about the bureaucratic practices in the hospital. What the hospital had done greatly disappointed her. Fong felt oppressed, but she was all alone and was powerless to fight back.

Fong: Yes. My friends in the hospital told me that when I was out to the bank to do some personal affairs, the nurse had come to look for me. I hadn't seen the nurse before that. The matter is like that. I had tried to give a letter to the manager, but he just had a meeting. So I went to see the nurse and told her that I wanted to give a letter to the manager. She asked for my name and promised to tell the manager about it. I asked them to give me a break of two weeks.

Then I came back to the hostel, for I wanted to be alone. When I returned to the ward of Sally, the nurse came in and told me that the manager wanted to see me. I finally met the manager and I told him my affairs. He asked me if there was any misunderstanding. I explained to him there was no misunderstanding, and that I was being bullied. I told him that I had asked for a break of two weeks to handle my husband's affairs. I left the letter to him and wanted it to be transferred to the Superintendent. But he said it was not necessary to pass the letter to the Superintendent.

On the next day, the manager asked the nurse to tell me that I could live there till somebody could give me help. That means I could wait until my families could hire a maid for me. I asked him to give me 3-4 months and I would leave in July or August. I had told the social worker too but he still refused to give me a chance and oppressed me. You should understand how much pressure was on me and nobody could help. You can only find somebody to help by yourself. Finally, I found Ah Yan (an ex-executive member of Direction Association for the Handicapped) and asked him to write a letter for me. I was relieved after I have been settled here.

Interviewer: Then did he always ask you to attend the meeting?

Fong: He had asked me to attend but I refused. I told him that was useless.

Interviewer: How did he ask you to have meeting? In the name of what?

Fong: His reason was that I was not a resident there and I had to understand my status.

Interviewer: That means you understood your situation?

Fong: Normally they refer to those who have gone home. After they acknowledged that my husband was dead, they thought that I should not stay in the hospital any longer. But the occupational therapist regarded me as unsuitable for going home for it would be dangerous for me.

Interviewer: Did the occupational therapist say so?

Fong: And he also said that I would think a lot if I went home and stayed alone. But nobody had any response there.

Interviewer: Nobody had any response?

Fong: No!

The social worker responsible for her case was unhelpful. Fong didn't trust him any more. But she was left helpless and didn't know where to get assistance.

Fong: The social worker said there was a clear division of labour so that the responsible worker was responsible for the case. Then the social worker said, there are social workers, doctors there, when you are in the long-term house, why wouldn't they help your case. I really didn't know. He said now we have to handle the case of your husband, and also your case. How did I know that? He only said these to me and I have told you already. He did nothing. He kept forcing me, hoping that I would leave. At last he wanted me to see him. He wanted me to meet him at 9 o'clock as he work on 9 o'clock, but I did not show up. I thought of it for a whole night. I thought it was not ok. So should I find Chan Tai Man or Lee Ho Yan? I called Chan Tai Man first, I asked for his help.

Moreover, Fong did not want to rely on her family.

Fong: Once the hostel offered a vacancy for me, I would leave. Actually, I could not support my home by myself alone after my husband passed away. I don't want to be a burden of my family, especially when the economic situation is so bad. Although my income comes from my several family members, I really don't want to border other people. The relations between my siblings and I have not been so good. We seldom had a talk or contacted each other. My father and mother asked them to give me a hand. That's why my siblings employed a domestic helper for me. Actually, I am not capable of employing a helper financially.

Fong had grounds to complain that the medical practitioners oppressed her since no assessment of her ability to live independently had been made. She understood that it was necessary to provide evidence to prove that she was unable to live independently before she was discharged from hospital. But the medical practitioners did nothing in this respect. All she knew was that a kind of eviction was implemented.

Fong:	Then the manager asked the chief nurse to tell me to have meeting. I asked her to tell them I wouldn't like to have meeting anymore. It was because the meeting was of little help.
Interviewer:	Then they did not disturb you anymore?
Fong:	They could do nothing with me then. I...
Interviewer:	Then did they ask you to do anything more?
Fong:	They asked me to go down there to talk with them. But I just didn't want to see so many people!
Interviewer:	Then did they ask you to have a medical check-up such as occupational therapy and physiotherapy before you left?
Fong:	No! No!
Interviewer:	That means you were able to live independently. (Fong: No.) Just to be told (Fong: Yes) If they did not check that means you had the strength.
Fong:	No! No! That means they didn't believe whatever you told them. Such as you said you couldn't take care of yourself and open the door.

This was not the first time for Fong to feel being neglected. When her husband was alive, they had once tried to convince an occupational therapist to help them to replace the battery for Fong's electric wheelchair. The occupational therapist refused to do it at once. The reason was that she could wait until the battery did not work.

Fong	I inquired to buy a new battery for my wheelchair. The occupational therapist rejected me. No wonder he wanted to oppress me because his excuse was that I could buy new battery

> only after the battery all ran out. I told him that it was always out of battery and it couldn't move. He said that was not the case. I asked him what I could do if it suddenly stopped on the road. He said in that case I could call the social worker. I argued that I couldn't call the social worker at anytime.

She continued to point out lack of sympathy for him on the side of the professionals. In addition, the professionals appeared to be trying to get rid of her. She had very bad feeling out of this experience.

Fong: I think he was just irresponsible. He just sat there but did nothing. He even didn't want to write something for us. But he could still get his good salary. Then I argued with him that if I had any problem or accident outside, he had to be responsible for it. He explained that not that he was unwilling to help but that he had to make sure if I had no battery to use. I told him that I felt it was run out of battery already. I said that he could check it. I applied for it because I had to use it, and not sell it to others.

> Luckily Ah Yan had been transferred to Heaven of Hope Hospital and he was responsible for this field. The nurses and social workers there are very nice. They would ask what we need and give us help. My husband then helped me to ask the social worker, who responsible for his case, to apply for the battery because I was using a wheelchair. The social worker promised but did not tell the difficulty. The hospital refused to help me because the social work helped me already. Actually sometimes they were right. Since I had the social workers, occupational therapists and medical doctors to help me, this hospital was not the only one who could render help. My social worker told me that once the hospital was responsible for the case of my husband, they had to take care of me too.

> I had asked the social worker here to help me but he didn't do it. Then I went to Bradbury Hospice. I told them I just needed one battery, and they tried to help me. The social worker of Heaven of Hope Hospital explained to them that I wouldn't sell the battery to others because I was unable to do so. And finally they helped me to get one. No wonder the occupational therapist claimed a small sized one for me though he had already checked the size of my battery and I had also told him it was a medium-sized one. When the battery was delivered to me, I asked if they had made a mistake. But they told me that it was written as this size by the occupational therapist. Fortunately, I was familiar with this

company and I asked them to give me the correct one next Monday. They really delivered a medium-sized battery to me on next Monday.

I had tried to contact the social worker and the occupational therapist but failed. It was because that was Saturday, and it was their day off. That I tried to find them was because it was the procedure I had to go through and I also wanted to justify how they could still make such a mistake as long as they had seen the size of my battery. I was disappointed as I always have to go out and the battery is very important to me.

After a series of events of interaction with the professionals, Fong felt upset and dismayed. She began changing her mind and thought what she should do. She persuaded herself to learn to live alone and be independent. This simply reflects that this is the outcome of her failure to convince the professionals to allow her to stay in a place that was convenient for her. Being unable to change the professionals' decision, she changed her mind and lived strategically instead. She also expressed her dissatisfaction with living at Cheshire Home. I am sure this was really what she felt. She appeared very much disappointed and desperate, and she even once wanted to commit suicide at that time. Seemingly, she had little confidence in her living alone, but she should change her mind to suit the 'reality'.

Interviewer: You said you are now living in the Cheshire?

Fong: My roommates always persuaded me not to be so serious-minded and asked me to accept the existing situation. The Occupation Therapists here are very troublesome. If it is possible, I would like to move out and do not live here anymore. I agreed with them. I told them I could look after myself and sure I did not want to live here. I think that no people would like to live with mosquito....

Interviewer: Would they close all the windows and turn on the air conditioners?

Fong: Air conditioners? If you want to turn on the air conditioner, you need to pay the fee. Because I have a dining room, I like to stay there rather than at the bedroom so that I needn't turn on the air conditioner all the time.

Interviewer: Always staying in an air-conditioned environment is not healthy.

Fong: Yes, I will turn it on at night time and turn it off at daytime. I like to go out for a talk with my friends. Also, at nighttime the security is very loose even though a nurse will walk around at 11 p.m., but afterwards they will not come again or do any patrolling until at 4 a.m. So in this period of time, no one will get to know if you are dying, or even you are dead. Your roommate may know your situation but practically all of us are disabled persons. It is difficult for us to depend on each other. When we have fallen asleep, no one can take care of you any more. So I often thought that people would die very easily in that period of time. I had talked with the social workers here and told them my intention of committing suicide. Do you really want to see me die? That is very easy. Just leave me alone here especially in the period of 4 a.m. to 5 a.m. A nurse will come and walk around and then leave and at about 6 a.m. she will come again and afterwards no one will come.

I had said before I wanted to have more rooms. I had not said that I wouldn't do any reporting work and even I was not keen on staying here up to the day I die. They forced me to leave and gave me no time to consider. They just called me to attend meetings with them. From the day I lived here, I talked with them in the meeting day and night. My roommates were not like me since they didn't need to attend the meeting with them frequently. They also felt curious and asked me why. I said I did not know.

Interviewer: From the beginning and up to now, you really do not know why they forced you to leave?

Fong: One possible reason is their existing system has been changed. That means no more disabled persons will be admitted here. I am not sure. You need to leave even though you are living here now. You can apply public housing or move to other hostels. I know many people have moved into hostels.

Fong went on to say that a person with impairment should figure out the right to take care of oneself. Her talk seemed to be directing to herself, reflecting her state of mind that she needed to continually convince herself of the fact that independent living was her only choice.

Fong: In fact, you are an impaired person. You should live in such kind of institution when you are getting old. You have not only just got your low part injured. If the function of your upper limbs is ok, there is no need to live into such kind of institution. In fact, your upper limbs are out of order. Eventually you need to think of how you live. Think of your future. It is fine if you receive assistance from family members. Family members can follow up your situation. But your family members will get old one day and then they cannot take care you. They cannot help you, for they are old. They have finished their obligation by then. Not that they are unwilling to help you but that they are incapable of doing so as they are old. They are to rely on their sons and daughters to support their lives. Hence, as an impaired person, you need to think of your future direction. You cannot depend on others for your whole life.

Fong did manage to live alone. She found she was able to deal with her life.

Fong: I think I am ok. However, my physical condition gets worsening recently. I did not expect that I would fall ill for several dates since my last sickness. I wanted to go to hospital but fever was lessened later. I kept on observing my condition till next night. Fortunately, fever was over and my condition was ok again. Fortunately, the doctor was so kind as to prescribe six days' medicine for me.

Interviewer: Antibiotics?

Fong: Yeah! Yeah! It was a heavy drug. This drug was of the old type. New bacteria were quite serious.

Interviewer: New bacteria?

Fong: Therefore, I need to take a new type of drug. Well, there are more problems when you are getting old.

Interviewer: Physical condition becomes worse.

Fong: I seldom fell ill even after twenty or thirty. Very seldom! It is because I have no problem of bed sore. When I am in a state of consciousness, I will not get bed sore even though I am sitting for a long time. If I got injured, I would recover very soon. People with consciousness and without consciousness are quite different .

Interviewer: That's your case.

Fong: Everyone is different.

Interviewer: You are feeling good. You don't need much care, no matter in the health or life aspect.

Fong: Well, therefore I don't know how to answer such kinds of questions.

Interviewer: According to your description, your lower limbs don't have any feeling so you need to pay more attention to them.

Fong: Just like the case of my husband, his lower limbs didn't have any feeling. However, he could look after himself and didn't need any help. All along, he could do all the things by himself.

Fong had only few choices. All she could do was to change her mentality. She relied on her own experiences that she could live alone since their parents had taught her how to manage to do things in her daily life. Fong is disabled, not only because of her impairments but also of the social environment where the professionals assessed her as she could live independently and made such a decision accordingly. She might not be convinced at first, but when it became a reality, her alternative was to change her mind.

Fong: I had lived in Aberdeen with my parents after I left the hostel. I always stayed at home and relied on other people. I needed help when I wanted to get something and even when I wanted to do anything. I felt I was useless. I wanted to learn some skills so that I knew how to live with my family. I didn't want to always stay with my father and mother at home. My parents took care me very well. However, I had to think about my future. I applied for a vacancy of hostel. Such hostel required their

> applicants to know how to get on and off from bed. At that time, I couldn't get on and off my bed by myself. In the morning, my parents and siblings would go out for work or buy things for me. They would take me onto my wheelchair. At night, they would take me back on my bed. So I usually practiced the on and off skill by myself at home for preparing the life of hostel. Anyway, independence is good.

Fong's story reveals her experience of a disabled. Her disability is social in nature in the sense that there were a lot of social but 'invisible' restrictions imposed on her life.

Case 2

Leung was a wheelchair user, with severe grade spastic since he was born. At the time of interview, he was living with his mother in a public housing estate. Because of his physical impairments, he needed to depend on his mother especially for caring his daily affairs. Despite of his impairments, he thought himself as being competent in self-caring. Leung said that 'even though the home helper can help, I still do what I can.' Nevertheless, he was no longer able to keep his ability in self-care once his health had become deteriorated. After that, Leung received home help service five years before when he found that he could not take well care of himself, especially in bathing. This was an unpleasant change, as Leung liked to take bath by himself for three hours. He enjoyed this simple activity. Leung only received bathing service or sought help from friend in bathing. He did the rest by himself because he enjoyed the freedom of choice in travelling and the consumption of food. In fact, having service from friends to help him to take bath, made him feel uncomfortable and regretful. Here is the transcript of an interview in which Leung told what he did when he was in need:

Interviewer: It is up to your choice, or it is up to the social worker from Social Welfare Department? Did they make the decision or you make the decision?

Leung: It is up to them. I would tell them my need. For example, for household cleaning, they would argue that your family would help, your mother would help. If they think it is not important, they won't provide the service. They would offer service to what they think the most important. A certain user may have several items in need, but nobody comes to help, and he needs household cleaning too. It all depends.

Interviewer: You previously said that it is the social worker who asks you first, asking what service you need, which items are in need, but the social worker make the judgment and the decision.

Leung: The home help team makes the judgment.

Interviewer: But at the end of the day is it the home help team or SWD to make the decision?

Leung: The SWD would play some part too, but only for referring. They would not make the judgment and it is up to the social worker of the team to evaluate what service you need, and then they give you accordingly.

Interviewer: Have there been any different views on that?

Leung: Sure. I had asked for 5 sessions for a week in summer, but they replied that it was impossible. I always had my view made known to them, but they insisted that it was impossible. They said that they had no way due to the limited resources. They argued that some other user would be left unattended if they allocated two more sessions to me. Their schedule was full. Yeah, like that (different view).

Interviewer: Did it affect you? To what extent?

Leung: Yes it did. It affected me very much especially in summer time

Interviewer: Any analogy?

Leung: It is really tough as I sweat a lot. I might force others to help me.

But they have to do it voluntarily. But it is very much up to them. It is only a kind of job whether they like it or not, they have no other choice. They may do it involuntarily. We need to consider their feelings. It is quite a hard job.

Interviewer: Is it difficult to get help?

Leung: It is difficult if it is really hot and I would like to take my bath for one more day, or if I am accidentally get dirty. It is difficult to ask help from others, but I would try, even it would loss face. Or I would handle it myself. But I lack the capacity as like as the helper.

Interviewer: Because of your stamina?

Leung: Definitely so. When I am taking my bath, it is always like "a war", and I cannot clean my body so thoroughly as the assistant. Perhaps I just wash it roughly, but if there is nobody there, I have to do like that.

Interviewer: Who would you like to call for help?

Leung: Usually my best friends, they may be those who used to help me through and through, so I would call them for help. There is no other way.

Interviewer: Ok, apart from helping you with your bath, what else do the assistants help? On your daily life?

Leung: I am relatively independent, except for something like bathing or wearing my shoes (that I cannot do). I would do all what I can handle myself. For example, it is more free for me to have my lunch and breakfast. I am personally a "free" person. I eat whenever I want and wherever I want. To be a free person would make me happier. It is no good if there is restriction. I guess except for bathing, there is almost nothing that I cannot do. Maybe except for getting dirty (accidentally), I feel at ease as to the other affairs.

Due to physical impairments, Leung could not go out to work even though he showed his eagerness. He faced many barriers in the job-hunting process. When he was at the age of twenty, Leung sought help from the Supported Employment Unit, but according to the assessment report he was not qualified to go out to work and was then transferred to a shelter workshop. Afterwards, Leung started finding jobs on his own. Therefore, he wrote forty handwritten applications letters to different companies but all ended unsuccessfully. With a view to hunting a job, Leung made efforts to call various companies at home. Throughout this process, he found there was no access for him to the working environment and the interviewers showed contempt for him. Finally, Leung came to the conclusion that he was not suitable for having a job because of the limited employment opportunities for people with impairments. He thought that it was at home where he could enjoy decent living standards.

Leung: When I left school, I was 21 years old. I need to find some jobs to do, so I tried to see what kind of job I could do. Because at that time, Supported Employment Unit was just established and so I went to that group for seeking help. The staffs of that unit said that as my academic qualification was not up to the requirement and my body didn't function properly, they did not know what kind of job I was able to do. Within two-month time, they let me take different jobs (packaging, collecting electric wires, etc.) for the purpose to test my ability. Their final result for my case was the transferal to Labor Department. As Labor Department had to identify the jobs that the applicant can do according to report of Vocational Training Council and the latter identified me as under the category of " not suitable for open employment ".

Interviewer: Not suitable?

Leung: They said so! I was angry at that time, Labor Department then recommended me to work in a shelter workshop. At that time, other people told me that shelter workshop was a place where people had nothing to do. I always thought that if the times went by in this way, I would feel so meaningless.

Interviewer: What were the crucial points of the Vocational Training Council's report that proved you not suitable for open employment?

Leung: It had some marks there but I forgot the contents of the report. The report was not open to public.

Interviewer: Could you see the report?

Leung: At that time, I could not see it but now I can take a look at it. When I asked the Vocational Training Council about this, its staffs told me that they had sent the report to my social worker. They said that I was not suitable for open employment and they suggested that I might work in a shelter workshop. That's all they said! There were some marks in the report and those marks were like those in IQ test.

Interviewer: Does the report include inability of four limbs and movements?

Leung: Yes! Vocational Training Council said that the assessment was very comprehensive, in around South East Asia region, I didn't know. I was just angry. I hadn't sought help from the rehabilitation team of the government at that time as I felt it was useless.

Interviewer: Why?

Leung: Because I felt that it shouldn't use this kind of assessment to evaluate individual value, I thought. I didn't care I was right or not. I shouted angrily at the staffs of Vocational Training Council. I said that they shouldn't use their standards to evaluate me and their report would affect my future, my career and confidence. From that time on, I had not sought any help from Supported Employment Unit either. There were nearly no institutional channels that could help me. I can only rely on myself. I wrote many letters, nearly 40 letters. You know, there were no copiers around at that time. Then I copied the letters one by one and then I posted them all. I was sure that I did not make any copy by copier and so I had to copy letters every day. Those were the hardest days, and you know, I wrote slowly. However, there were no replies of the letters.

Interviewer: Did you make known in the letter that you were physical impairment?

Leung: Yes! But there were no replies and then I used phone-calls to find jobs. I could find those phone numbers in the newspaper and it was lucky that I was interviewed for several jobs. However, those experiences made me unhappy. At that time, I was only 22 years old with no further studies. As there was no electrical wheelchair, I couldn't go to the interview place by myself as I could not propel the wheelchair and the interview place was very difficult to get to. Then my friends propel me to the interview place. When I enter the society, there were many things that I hadn't come across before. There were sufficient facilities in the special school but there were no such facilities in my home and in the working place. I felt very inconvenient in those places.

Interviewer: For examples?

Leung: For examples, in several locations where I was interviewed for job, there were staircases blocking my way. I had to ask the by-standers to help me. After that, there was a lift and so it was a commercial building! And once, when I was interviewed, I was tested to take the phone-call and the phone-call was in English. Because my English was not so good at that time and so I could not speak well. The interviewer laughed at me and told me that I need not come again. He asked me why I was so impolite in the conversation. Now, it is better. The interviewers will ask you to wait further call or letter and it make me feel more comfortable.

Interviewer: How about second interview?

Leung: No! No chance. I got to know it. I had an interview for a few jobs for jewellery polishing. I didn't care I could or couldn't do it, but I guessed that I couldn't do it either. I only wanted to take the interview, but the interviewer didn't say anything to me and it made me so uncomfortable. After that, I did not go to any interview again because they made me so unhappy. They shouted at me and said, "You (dead handicapped), you are brave enough to come for the interview." I would never forget that sentence and I couldn't imagine those words would come out of those people's mouths. You see, discrimination was so severe at that time. After that, I hadn't gone for interview any more. I did some simple handcrafts that I would like and did self studies at home.

Interviewer: What do you mean by "self studies"?

Leung: Reading English! At that time, there was no computer. I remembered that I had nothing to do except reading books. Everyone did look down on me. You know that my leg couldn't move and I had no electrical wheelchair. So I had stayed at home all the time.

Interviewer: Reading books? Is it what you called "self-studies'?

Leung: Other people talked, I listened. At that time, I had moved to X X Estate and I stayed at home and read books. So boring!

In Chapter three, I have mentioned the experience of Leung in seeking help from the police at midnight when he found that the lift was out of order. Leung needed to face many challenges in every aspect in his life. Travelling in public transport is one of the challenges that Leung needs to deal with in his daily life. The mal-functioning of the electrical ramp and the bureaucratic management of the wheelchair lift in the Metro Railway were those situations that made Leung feel embarrassed. Leung complained: "I reckoned that our human rights have been relegated to a secondary status. Our needs have not been recognized so that our time is not as valuable as that of the other people.... I do not think it is a kind of neglect but it is out of disrespect."

The disabling built environment, which Leung encountered, which made him feel inferior. But when he compared this experience with that arising from his relationship with the helping profession, the latter was regarded as more unpleasant. Leung attended regular medical check up and expected to maintain friendship with the helping professionals. Nevertheless, he found himself treated as a 'case' in the eyes of the professionals. Leung felt disappointed when he talked about the relationship with the helping profession.

Interviewer: What kind of services you are now using?

Leung: Physiotherapy. I need him to buy the wheelchair.

Interviewer: To make the assessment.

Leung: Yes.

Interviewer: Do you take regular professional check up?

Leung: No, I usually contact him when I have to buy something.

Interviewer: They would help you to do the assessment, for instance, in buying wheelchair. Which type would they suggest?

Leung: They would teach us.

Interviewer: Any particular function of that type?

Leung: Yes.

Interviewer: They would help you in assessment?

Leung: They would measure it carefully

Interviewer: To measure the scale?

Leung: Yes.

Interviewer: What do you think about their attitude in doing the evaluation?

Leung: I guess they treat us like a patient

Interviewer: So what do you mean?

Leung: They treat it like handling a case. In case you want to buy something they would help you in finding one. However, I take the physician that I meet as my friend. I think so. But I am not sure whether they would treat me as their friend in return. I hope there is more other than just asking for his help; we can talk more simply and naturally. I would hold such belief. I don't know whether they think in the same way. They might handle it like working on a case.

Interviewer: Stick to formal procedure?

Leung: Yes, it seems very structural, bureaucratic.

Interviewer: Does it affect you?

Leung: Sure. For example, let me illustrate how they behave like a bureaucrat. They have to consult their superior. Sometimes I asked whether I could borrow something, perhaps you had it in the centre, but they couldn't offer you, even for only a few minutes. It seemed that I would break the item. It seemed so "impersonal". Even I was quite curious about that item and wanted to borrow it, but they would usually reject me.

Interviewer: Did they think you would break the item or is it that the rules to blame?

Leung: Not very good. They didn't want to spend time explaining it in detail. For example, if I saw one thing (on rehabilitation) really interesting, they would not have the time to explain it to me.

There might be many functions and I wanted to know them in detail. That's it. I don't think it appropriate. I hope they can treat me just like a friend.

Leung felt dehumanized. Just as any one of the non-disabled people, he liked to be treated equally and fairly. He expected people would interact with him in the ways similar to other non-disabled people in disregard of his impairments. However, the social and the built environment disabled him and his bad feelings were out of the disabling and exclusive social environments rather than his physical impairments. It is the visibility of his physical impairments that had been taken by the public as evidence of the constraining body and as a result the public avoided him.

Case 3

Hang was a young man in his thirties with quadratic, visual, hearing and speech difficulties. At the time of interview, he was living with his parents in the public housing estate. Before being attacked by brain disease, he was filled with confidence in himself. At his workplace, his boss had showed appreciation of his performance and working ability. As a smart young man, his future had been somewhat promising. However, he worried about his parents since his mother had suffered from kidney trouble. His father was in his seventies. Due to old age and illness, the parents found it difficult to take care of him. After having physical impairments, Hang felt the pressure from performing the tasks of taking care of his parents. Housework was demanding and Hang felt exhausted. Hang expressed such worry in the interview. But I noticed that his mother also worried about him since it was risky to leave him alone at home:

Hang: Sometimes I went to hospital alone. I attended regular medical consultation section and got medicine. My parents are too old to take care of myself. My mother has also suffered from kidney malfunctioning. So, I need to try hard to train up myself, such as helping myself to get a glass of water. My parents sometimes went out. As my mother has suffered from severe health trouble, she needs my father's assistance. My father escorted my mother to go for medical consultation. My mother's health gets worse recently.

Hang's mother: Sometimes we need to go out. We cannot stay at home all the time and keep an eye on him! It is impossible to keep us at home all the time. Of course, we sometimes need to go out to do something. I need to attend medical consultation.

Interviewer: Yes, Yes!

Hang's mother. Sometimes we were afraid to leave him alone, even toileting

Hang: Yes! I cannot go into kitchen to get food if no people at home.

While Hang worried about his parents, his parents in turn pushed him to commit to rehabilitation training at home. To his parents, this kind of training could equip him to take care of his daily life. Moreover, his mother's eagerness of pushing him to train up himself was in an attempt to transform him into an independent person. The following dialogue shows Hang and his mother's concerns:

Interviewer: Which aspect of help, for example?

Hang: For example, professional treatment, for me, I am a physically handicapped (severely). For example, I cannot turn on the water heater at home by myself. I cannot go out, I cannot live without the electric wheelchair, and without the electric wheelchair all would be in a mess. If I go to have service from the occupation therapists, many things could be ok, I can take care of myself. You go and have you hair washed, go to the hospital, it could be ok.

Interviewer: As it is the result of being trained gradually, so that you are able to put things right?

Mother of Hang: Yes, I hope he can handle them by himself. He is really bad. If you do not help him, he can't help himself.

Interviewer: Yes, it is the common practice for everybody.

Mother of Hang: It would be better if there are others to help him.

Interviewer: It would be better.

Mother of Hang: He should try to walk a bit more, and then it would be easier for him to go to buy a piece of bread, to go to the kitchen. I ask him not to be so lazy.

Interviewer: To get more practice.

Mother of Hang: Right...

Assisted by the home-based occupational therapy service, Hang tried to train up himself in self-care. He believed that improvement in self-care ability could help him to become more independent. In the above dialogue, we notice his mother's dissatisfaction with Hang's condition. His mother expressed her wish that Hang's mobility condition could be improved. She hoped Hang could improve himself to the extent that he could exercise self-care, such as going toilet and doing cooking independently. In his mother's view, Hang was lazy and learned little to enhance his ability in respect of mobility. Hang was blamed for his laziness. Moreover, Hang's mother also felt exhausted and anxious about her ability of taking intensive care of his son. She pointed out that she had difficulties in taking daily care of Hang. She also complained of herself being confined within her home.

Nonetheless, Hang regretted giving trouble to his parents. He knew his father had been working very hard in support of their family. He also worried about his mother's illness. He had promised himself to learn more and to do more exercises to enhance his mobility. We knew he wanted to support his family. He interpreted this task as the responsibility of a son. He did not try to avoid this responsibility. Supporting his family appears to be evidence showing his worthiness in his being.

Satisfaction with Hang's accomplishing his family responsibility seemed outweighed his dissatisfaction with his experience in daily life. He pointed out that he experienced many discriminative treatments from people in the street. He felt disrespect from the people. He found it strange to see that parents allowed their children to show no sympathy for people with impairments. They even did not stop children showing inappropriate behaviour towards him. In face of such a situation, he felt ashamed and uneasy. He expressed his feeling in the interview:

Interviewer: The topic that I just want to discuss with you is that, what do you think of the atmosphere of our society in respect of the treatment of the disabled? That's to say the habits of the people. What attitude do they take towards the disabled?

Hang: Some of them are really discriminate against the disabled; they won't understand that to be unlucky is unnatural. In fact, all parents on the earth do wish their children could grow up healthily. If mishaps do not come upon you, you are not in a position to feel them. You cannot imagine that a person who got to work everyday like anyone else and suddenly has become severely handicapped one day. Who would ever have a thought of that?

Interviewer: You have mentioned that some of them were discriminating against the disabled.

Hang: I feel really upset about that.

Interviewer: You feel upset?

Hang: You wouldn't want this kind of thing to happen on yourself, would you?

Interviewer: No, nobody wants it to happen.

Hang: Yeah, without my legs I find many place inaccessible. For example, I really wanted to go out and watch a movie, to go out, to go to the church, to be more close to God (go uphill), go camping with the Christian brothers/sisters, go camping, go anywhere....suddenly you lost your leg. I feel really shameful, very upset.

Interviewer: With regard to discrimination, in what way did they discriminate against you? You guess what kind of attitude they have taken?

Interviewer: Some would help, but some won't?

Hang: No, they would just go straight, leaving you unattended, that means discrimination. I'm afraid that, for example, I took a lift in a plaza to a food shop. In the lift there were about ten persons, one of them was a small child. The child pointed at you and said "this man/woman, why does his/her eyes/mouth/limbs look(s) so different?" Why didn't the parents teach their children to be right on this kind of issue? They might be struck by bad fortune one day, e.g. traffic accidents, or get sick. They (the handicapped) did not want it to happen. Did they do wrong so that they have to suffer from disability? No! But they just laughed, the children were laughing, they could't tell what's right and what's wrong. But you were an adult already, they should know it is inappropriate, but had they done anything to stop their children? No, just laughing and laughing. I have my dignity too, I need others to respect me. It really upsets me.

Interviewer:	You mean that the parents did not teach their children well in this regard (Tse: that's true). They should teach them how to get along with the physically disabled correctly, for example, when they saw you? The children would point at you and laughs, making you feel very embarrassed. They paid no respect to you.
Hang:	I hope the media and the society will help to transmit the message that to be lucky is not necessarily natural.

From everyday life, Hang experienced bad social attitude towards him. Children laughed at him for his physical differences. Under this situation, he felt embarrassed and being not respected. He strongly proclaimed that he had dignity as any ordinary people. He felt dismayed when the non-disabled people treated him with discriminative behaviour. Hang expected that mass media would deliver the message of "fortune is not a must" among the public. He thought that such message might lead people to think about the specific needs of the people with impairments and their situations and in the end discriminative atmosphere in the society would be eradicated. In response to discriminative attitude, Hang tried an indirect way to deliver message to the masses that equality and respect were important to our community. He wanted to serve as an ambassador to promote the rights of the impaired people and to raise people's awareness of the wrong exclusive measures in the built environment. He did participate in an annual election for brave disablists. The purpose of his participation was to promote the rights of people with impairments. As he proclaimed in an interview: '[I] hope to awaken people's consciousness on sufferings. Sufferings come from this disease, traffic accident, etc. For example, like me, I got brain damage, then difficulties in hearing and speech and quadratic impairments after a brain operation. I hope to reduce people's discriminative attitude and misunderstanding. Wheelchair users are not rubbish and useless. Don't hold discriminating attitude. I want to encourage disabled people to try their best. As to me, now, my father and mother are getting old, and have bad health. I need to work hard. My father has to escort my mother to attend medical consultation. And, he also needs to handle household works such as preparing dinner and washing clothes. My father works quite hard. I feel so sorry for my father because I cannot assist him. So if I can take care of myself, that is good for ourselves." In fact, Hang wanted to be independent, both inside and outside his home. Despite negative experience of being discriminated, he remained an active citizen, working and struggling for his well being.

Summary

Strictly speaking, the detailed accounts cited in the previous section are unrepresentative in a strictly statistical sense. I also notice the absence of variations in the types of impairments included in this study. In spite of focusing on the wheel-chair users, what I attempt to illustrate is not to draw attention to the differences between the lives of disabled and non-disabled, but, on the contrary, tend to put the stress on the 'sameness' or the 'shared features' of disabled and non-disabled people's lives as a whole.

In the case of the elderly lady, her experience with the social workers and medical practitioners, is a case revealing the dominance of professionals and the appalling outcomes of strict bureaucratic attitudes. Under the surveillance of professionals and bureaucrats, neither disabled people nor non-disabled people could enjoy independence and reasonable provision of social services. This reflects the ordinariness of the socio-economically disadvantaged people. Of course, apart from the general problems in ordinary life, the lady experienced a particular process of exclusion that is to a large extent due to disability. Without personal capability of handling her housework and being unable to live independently, she needed medical services and a place in Cheshire Home. Strict regulations on the duration of staying made her ineligible for staying there and she was even subjected to continual inquiries and investigations – to the elderly lady, these were intrusions into her personal life. She was upset and felt confused about her ability to live independently. She also felt powerless and vulnerable to bureaucratic intrusions. To her, it was unsafe to be living independently but she seemed to be ineligible for staying in any government-run nursery homes. Despite these, however, she took 'exit' as her form of resistance. She did not show up in the ensuing case conference. After the occupational therapist refused to change battery for her, she asked a social notable to write a complaint letter to a nursing officer. Although these actions had not brought any promising results, she did attempt to challenge the overwhelmingly bureaucratic institutions that restrict her mobility ability and affect her well-being.

Leung did not feel much frustrated from his physical impairment. He thought that he was qualified to work. However, throughout the process of job-hunting, he was upset and finally came to the conclusion that he was unable to work. The long process of job-hunting and the ensued failures and frustration changed his identity from one being able to work to the one being unable to do so. Such feeling of disability did not come from his impairment but from the exclusive social environment. The impolite responses of the people at the workplace, as well as the indifference of the policemen and the security guards, were the factors giving rise to Leung's disability. He attempted to treat the occupational therapists and physiotherapists as his friends but he knew he was just 'a case' to be handled by these professionals. Certainly, he felt dehumanized, inferior and disreputable. Anyhow, we see that he remained active in job seeking.

He sent forty hand-written letters to various companies. He complained about the poor services of the bus company. The dominance of his life is not full of personal tragedies but active social participation and resistance.

Hang appeared to have experienced the pressure from his mother who believed hardworking was an essential character for anybody living in a capitalist society. On different occasions, her mother blamed him for being lazy, not making more efforts to train up himself as an able person. She expected him to be a productive person and to be integrated into the mainstream of society. However, Hang understood that he was not easy to enjoy the normal life outside. Children teased and laughed at him who eventually felt the full negative weight of social discriminatory attitude. He was dismayed and distressed. His optimism came from his confidence in education, with a view to enhancing communication and mutual understanding between disabled and non-disabled. In fact, in his mind, people's reaction to his presence was not his main concern; instead, he was concerned with managing his parents' lives. His social life wherein he was treated differently and impolitely had not brought him much damage to emotions and self-esteem, while his parents' health and livelihoods exhausted him. Similar to any carers, what Hang valued most was family life. Despite physical impairments, he played the role as a carer contributing emotion and efforts to the well being of his dependents. By playing this role, Hang's identity as a worthy person was thus enriched. He talked about his contribution in being able to be a proper carer of his parents, and showed that impaired status would not necessarily lead to disability. In other words, despite the profound unhappy experiences of social exclusion, people with impairments are not necessarily 'passive victims' of oppression.

- End -

Chapter 5

Impairment Effects and Its Psycho-emotional Impacts

Let us revisit the two key concepts employed in this study, namely disability and impairment effects. Regarding the definition of disability, Thomas's analytical framework of disability study has been taken into consideration and started off with a distinction between two social definitions of disability. The first is a social relational definition of disability which, as suggested by Unions of the Physically Impaired, refers to 'the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have...impairments and thus excludes them from the mainstream of social activities' (Thomas 1999:40). Here disability is a social relationship between people, or put it in other words, disability equals to the social imposition of restrictions of activity on impaired people. The second definition of disability commonly known as property definition and used by social modellists is actually a variant of the definition of International Classification of Impairments, Disabilities, and Handicaps, that is, disability is a property of the person with impairment: 'a disability is any restriction or lack...of ability to perform an activity', or disability is amount to 'restrictions of activity experienced by people with impairment' (Ibid.:41).

Thomas took the first variant and put emphasis on the 'social' impositions of restriction of activity on impaired people. However, this definition does not entail that "all disadvantages or restrictions of activity experienced by people with impairment constitute 'disability'. That some restrictions of activity may be directly associated with, or 'caused by', having a physical, sensory or intellectual impairment (not being able to do certain things because of the absence of a limb or the presence of chronic pain or fatigue, for example) is not ruled out – it is just that these are not 'disabilities'" (Ibid.:42). Here comes Thomas's distinction between disability and impairment effects. Thomas reminded us of the importance of the study of the impairment effects in the sense that 'the restrictions of activity which are associated with being impaired but which are not disabilities in the social relational sense. Impairment effects may become the medium of disability in particular social relational contexts' (Ibid.:42). She further reminded us of not seeing impairment effects as the effects of the biological or the natural, or as a pre-social phenomenon. These effects are profoundly bio-social, being the outcomes of the interaction of biological and social factors as well as being bound up with processes of socio-cultural naming.

If we look at the 'lived experience' of people with impairments, the outcome of the interaction of disability and impairment effects would be discovered. Lived experience is the products of such an interaction, which constitutes the personal experience of the impaired people. As Thomas argued, "in a society in which the dominant discourses attribute all restrictions of activity to the 'tragedy' of impairment, it is of great political significance to conceptually separate out disability from impairment effects' (Ibid.:43). In our view, making this analytical separation is not only of political significance but also of academic significance. In the following sections, we show that medical practitioners, with their dominant bio-medical discourses, consistently imposed their somewhat understanding and interpretation of the personal experience of impairment on their clients whereas the 'clients', in their own language and narratives, gave alternative understanding of their own experience out of impairments. It is at this point that we can see social struggles taking place. Thomas has given the justification for the study of impairment effects in a way that 'these are the direct effects of impairment which differentiate bodily functioning from that which is socially construed to be normal or usual. In our society, these impairment effects generally, but not always, become the medium for the social relational enactment of disability: social exclusionary and discriminatory practices' (Thomas 2002:20).

With this view, I argue that there are tensions between the disabled and the non-disabled. Medical practitioners attempt to interpret clients' impairment effects as the experience that can be categorized as 'unusual', 'different from that of the normal people', and 'commonly felt by disabled' while the people with impairment may have their own interpretation that should be seen as quite personal and not unusual. I expect to show that the struggle taking place here reveals the possibility for the people with impairments of resisting the dominance of bio-medical knowledge. This is the area where we can find the political significance of the feminist slogan 'personal is political'. In the following section, I will cite the experience of the wheel-chair users from the transcript to show how they resist the dominance of the bio-medical knowledge on the basis of their experience of impairment effects. Furthermore, I will highlight the psycho-emotional dimension of the impairment effect. Lastly, I would say that our interest in the study of the experience of people with impairment lies on what the experiences of individuals with impairment can tell us about the nature of disablism rooted in wider socio-structural and cultural contexts.

How did individual experience impairments?

Similar to disability, impairment effects have two dimensions which interact on each other: first, factors and processes which serve to restrict activity, that means, what and how people with impairments are doing; and second, factors and processes which undermine psycho-emotional well-being, that means, how people with impairments are prevented from being. In this section, I will explore these two dimensions of the impairment effects in the experience of the wheel-chair users in our studies. I have selected five cases for this purpose. The reason for the selection is simply that their experiences clearly demonstrate the interaction of disability and impairment effect in the process of dealing with medical practitioners, and in other words, they reveal how impaired people, as an active agency, resist the dominance of bio-medical knowledge.

Case 1

Lan was a young lady in her twenties. At the time of interview, she was living with her son, about seven years old, and her aunt. Owing to the deterioration of her health, she needed to use electric wheelchair. In her daily life, she shared domestic work with her aunt who acted as a carer looking after her in several aspects such as bathing, cooking and household maintenance, etc.

For the deterioration of her physical functioning, Lan felt quite upset and worried. She complained of her being too young to become a wheelchair user several times. She nursed great sorrow for her physical deterioration. She wished her health condition would not go on to deteriorate to such an extent that she had to give up any hope of improvement. Though medical practitioners believed that her condition seemed to remain unchanged and she got emotional frustrations, she had some ways to cope with such situation. Lan had her own way to deal with her situation. The following transcript of an interview with Lan disclosed her frame of mind on her life:

Lan: I find that the toilet is not suitable for use now. Several years ago it was ok and I could get access to it without needing to use the handrail at that time. However, some years later I found I couldn't get in to take my bath or wash my hair. I even couldn't put my wheelchair in. I felt upset. Many disabled persons take their bath using a shower chair.

Interviewer: Shower chair?

Lan: I have no shower chair so that I cannot get in. Besides my wheelchair cannot get in either.

Interviewer: Is that so?

Lan: It is quite contradictory.

Interviewer: Yes!

Lan: I want to keep my health in good condition. I don't want it to get worse.

Interviewer: Sure.

Lan: Naturally we cannot take our health in our hands, but I hope I can keep it in good condition. I hope it won't get worse too easily.

Interviewer: What will you do to keep your health in good condition?

Lan: Be happy! Eat more nutritious food and do more exercise!

Interviewer: Are these recommended by the medical officer or nurse or your own opinion?

Lan: It is my own opinion. Honestly speaking, the medical officer and the physiotherapist are not really of much help. You know our society is suffering from economic stagnation currently. I find it is very difficult for me to do anything even I want to do.

To Lan, "be happy" and "eat more nutritious food and do more exercise" have become an effective way to cope with her physical deterioration condition. This seems to be common sense to others. Medical practitioner couldn't do any more in her case. However, it seems she didn't easily give up her hope of preventing the situation from getting worse. Although she felt terribly unhappy for the deterioration, she still tried her best to find a way to deal with the situation. She cherished the hope that she might keep her health in good condition, and to achieve this, she tried to do a good job in both emotional and nutrition aspects, though she faced economic difficulty. The following dialogue shows how Lan tries hard to struggle for dealing with her impairment:

Lan: Yes! I hope my health condition will get better in the near future.

Interviewer: Is it really the case?

Lan: Sure, I do hope my health condition won't get worse.

Interviewer: Won't get worse.

Lan: If my muscle atrophy condition gets worse, I need to sleep in bed all the time. Then I would get inflammation and complication may occur.

Interviewer: You're right.

Lan: I hope I could keep my heath condition on as it is now.

Interviewer: Have you got complication?

Lan: Fortunately no.

Interviewer: When you felt your health condition got worse, you would probably feel the pain.

Lan: I would have cold, headache and dizzy and was easy to get tired.

Interviewer: I see.

Lan: Sometimes, I couldn't sleep. Many disable persons have the same problem.

Interviewer: Why! Due to the pain or because you felt unhappy?

Lan: Many reasons. Feeling unhappy is one of the reasons. The feeling of pain in my bones and hands is another reason.

Interviewer: Pain in your bones?

Lan: Pain in the waist part, too. Just now when I was talking to you, I felt pain in my waist

Interviewer: Which parts do you feel pain?

Lan: The waist, hands, feet and the bones.

Interviewer: Oh, I see.

Lan: Sometimes, I would take part in some activities so that I could move my body and stand up for a while.

Interviewer: You need to sit down for a while and stand up for a while. Then you will feel better, is that so?

Lan: However, the medical officer didn't give me any medicine.

Interviewer: No medicine?

Lan: From the very beginning I haven't received any medicine at all. I just took a rest when necessary.

Lan's life is full of pain and unhappiness. Pain made her awakened. This certainly is the indication of impairment effects. Pain not only prevented her from being mobile and affecting the 'doing' aspect of her life. It also brought her unhappiness, an indication of her 'being' being affected by impairment.

However, impairment does not work independently, it was interwoven with disability effect that resulted from the practice of medical officers. It was because, as she indicated "honestly speaking, the medical officer and the physiotherapist are not really of much help." Her deterioration seemed impossible to make any improvement or, in other words, her situation was incurable.

Despite deterioration and incurability that upset her very much, she still struggled for her betterment. Lan's case has nothing to do with sick or victim role. She stated that she would not isolate herself from outside again. She knew it was up to her choice whether she was optimistic or not towards life. There were some ways to handle her physical problems: to take a rest or to lie on the bed were her usual methods to release her pain. She kept on doing so with no thought of the effectiveness of such practices.

The methods used by Lan to manage her deterioration and pain were common for other people, especially when no special treatment or radical method was suitable. The significance of Lan's case is that she acted in line with her determination. She prevented herself from getting in touch with the mainstream social discourse, which regarded her deterioration situation as incurable. She hoped for stability of her physical condition. She hadn't shared such a negative attitude of hopelessness towards her life. Social attitude towards deterioration of chronic illness had little effect on her life. Lan asserted that she was willing to face the reality and would encourage herself to look for happiness in life. She would make friends with other people and let them share her feeling. She also thought that her appearance in the public area would lead the ableists to make reflection on their lives. When the ableists see her and share her strong will to fight for happiness, they might be enlightened to rethink their foolish acts, such as suicide.

Moreover, although medical experts could do little for her, Lan insisted on doing what she could and what she believed she could cope with her physical problem. In her case, she adopted the common health maintenance methods, such as to be happy, to have nutritious food and some appropriate time for rest. These methods are not particular ways in health maintenance, but to Lan, they are still important. In the medical point of view, as Lan said, medical knowledge and technique just contribute a little to her problem. However, she resisted accepting the assertion that her case was incurable, though she worried about that at heart. She tried her best to do a good job in her health keeping. The notion of incurability failed to affect her life very much. On the contrary, she sought for her own ways to handle her physical problems and constructed her life anew. And she tried to help the ableists with her own image to reflect their lives in social interactions. From that, we can see Lan had nothing to do with victim role from medical discourse. With efforts and vigour, she developed a strong character enough to face difficulties in her life.

Case 2

Ah Wai was an electric wheelchair user, with quadratic impairment. His injury was caused in a traffic accident that happened more than twenty years ago. He stayed in hospital for several years for medical treatment and rehabilitation training. He was living with his younger brother and a domestic helper in a flat under Home Ownership Scheme. Owing to his severe impairment and limited mobility, he depended on his domestic helper to do the caring job and most of the daily affairs.

On the other hand, Ah Wai had to deal with the problem of seizure and the prevention of bedsore. He had his own ways to deal with these. The following dialogue shows how Ah Wai accounted for his tactics, especially his experiences in selecting cushion. To prevent bedsore, it is most important to choose the appropriate cushion.

Ah Wai: It should be noted that bedsore could cause death. The wound would deteriorate into a large area, and then it would become bigger and bigger.

Interviewer: What could be done then?

Ah Wai: The decayed flesh may be removed or a small piece of flesh cut from the thigh may be used to fill up the wound. The size of the wound may be as big as an egg.

Interviewer: Wow!

Ah Wai: It would deteriorate and the wound would develop bigger and bigger! That's it

Interviewer: Then you must go to the hospital to have an operation, for the situation is so dangerous.

Ah Wai: You are right. Bedsore should be prevented.

Interviewer: Is there some time when people are vulnerable to getting bedsore? Such as summer, winter or spring?

Ah Wai: Yes, there is. You need help if you sit on a wheelchair. As your hip and pelvis are closely in touch with the cushion for a long time, the blood in them does not circulate fluently enough. It is just like the case of playing Majok, you have to change the seat after you have played for some time. You know we have lost the feeling of pain.

Interviewer: Hum…

Ah Wai: Bedsore would cause the wound to swell and deteriorate. Then the blood is unable to flow to the affected area.

Interviewer: Hum…

Ah Wai: If you feel your body deteriorates, you have to take care of yourself and ask some one to help you to relax. It would be better even to relax for one or two minutes. The blood can flow more fluidly if you can leave the cushion for some minutes from time to time.

Interviewer: Then your buttock would be relaxed.

Ah Wai: Yes!

Interviewer: This is the way to prevent you from getting bedsore.

Ah Wai: Yes. That's right.

Interviewer: How to call the cushion you are sitting with

Ah Wai: It is called Sea Horse.

Interviewer: Oh, I see, it is the cushion of Sea Horse brand.

Ah Wai: There are some holes in the middle of the cushion to let the airflow. People have different preference. Somebody likes to sit on RoHo and so on. Each (RoHo) is worth several thousand dollars.

Interviewer: What is it then?

Ah Wai: It has some balls in it.

Ah Wai said that medical practitioners liked to recommend using RoHo, but Ah Wai did not think that an expensive cushion like RoHo would be better than See Horse. He thought that medical practitioners sat on it just for a few minutes and never got the same feeling as the one that sat on it for a very long period. People with impairments felt differently since time mattered.

Interviewer: It's a plastic one, which has an uneven surface.

Ah Wai: Yeah. That is RoHo.

Interviewer: Each one is worth several thousand dollars?

Ah Wai: Yeah! But it's much cheaper now. Now it costs around two thousand dollars, but still very expensive.

Interviewer: It's a cushion for sitting.

Ah Wai: Yes. You've to pump some air into it to make it like a bubble. I don't understand the theory but I can check up the manual. But I've some experiences of sitting on some poor one. I'm used to sitting on Sea Horse. Everyone has different habits.

Interviewer: The most important thing is your own feeling.

Ah Wai: The most important thing is to sit on it comfortably and there's no problem when you're sitting on it.

Ah Wai was keen on choosing appropriate cushions based on his rich experiences. He differentiated various types of cushions in their price, design and quality. Moreover, he reminded us that the fundamental principle was one's feeling: comfortable and no problem would be involved. Here reveals that impairments had impacts on the lived experience of people with impairments.

Despite his serious physical problems, Ah Wai showed his confidence in health maintenance by himself. His confidence in health maintenance expresses in two ways. One is making use of lived experiences to cope with physical problems and another is the assertion of counter narrative to medical or professional knowledge.

Firstly, we discuss Ah Wai's lived experiences to cope with physical problems. Ah Wai was quite keen on various rehabilitation equipments and medicines. He accumulated a lot of valuable experiences in handling different problems. In the following, his experience has been illustrated:

Ah Wai: I am taking a kind of sleeping pill called VALIUM to help me to sleep more easily.

Interviewer: Yes.

Ah Wai I have to take anti-depression to prevent seizure.

Interviewer: That's a kind of sedative drug.

Ah Wai Yes.

Interviewer: It can help to prevent seizure

Ah Wai Yes. My legs would move uncontrollably if I don't take it.

Interviewer: Do you mean your legs would get seizure if they move too much?

Ah Wai Seizure means my legs would move uncontrollably. As a matter of fact, my brain is unable to control it. My vertebra was injured when it bumped against the table. Since then I have to take anti-depression.

Interviewer: How much do you take per day?

Ah Wai I just take it at night. Just once per day.

Interviewer: Once per day before sleep.

Ah Wai I mean I take the medicine before going to bed. Just a pill per day.

Interviewer: Did the doctor remind you of keeping health and of preventing seizure from occurring?

Ah Wai They regarded it as a common case.

Interviewer: So you could do nothing to deal with it.

Ah Wai I can do nothing in respect of my case of neck injury. The most important thing is to prevent bedsore.

Interviewer: No, you can't.

Ah Wai This is the most important.

Interviewer: Then how to prevent?

Ah Wai To turn the body over when I am sleeping. I would ask others to help at night. Sometimes turn over to the right and sometimes turn over to the left. I am used to being helped by others. Sleeping on an airbed is another solution.

Interviewer: I see.

Ah Wai Airbed is a cushion bed. It is a very basic knowledge.

Based on his rich experience gained from handling his physical condition problems and in choosing rehabilitation equipments, Ah Wai further commented the judgments and opinions of the medical experts. This was shown from the following dialogue:

Ah Wai:	Yeah! It's nothing to do with the price, for an expensive one may not be a good one. Those experts just try to convince you to use the expensive ones. They are not users, so they are theory-oriented. They would introduce RoHo to you if you asked them. It's because it's the most expensive. Actually many people got bedsores after having used it. It may not be the case, but you have to choose the suitable one for you.
Interviewer:	Hum...
Ah Wai:	And you need to understand the impaired more. But one often wants to get more information, and you have to depend on the experts.
Interviewer:	That means the disabled would exchange their ideas and experiences.
Ah Wai:	That's right.
Interviewer:	Just like using XXX last time.
Ah Wai:	Yes. It is just like the case of participating in some associations; there you can contact more users to understand the problems. If you just depend on the physiotherapists alone, what you got from them is the knowledge they learnt at school.
Interviewer:	Hum......
Ah Wai:	But they have not tried to sit on it.
Interviewer:	Even they tried to sit on it, it would be just a short while.
Ah Wai:	Yes. Actually they would not try to sit on it to experience the sensory feeling. As they are not impaired, they don't really know the problem. We are in a position to understand the problem as we've used it for a long time. Everybody has his or her own need, so some people feel good to use RoHo.
Interviewer:	Hum...
Ah Wai:	I don't mean it doesn't work for everyone. RoHo suits some people.
Interviewer:	Oh, I see.
Ah Wai:	But it doesn't suit some other people.

Interviewer: Hum…

Ah Wai: Everybody has his or her own need. What's expensive doesn't mean the best.

Interviewer: Hum. I know the lower part of your body has lost feeling. Sometimes you would have inflammation or pneumonia.

Ah Wai: Yes. I would always have a tube inserted into the bladder, and this would be infected easily. The doctors said that's inevitable, the problem being how frequently it takes place.

Secondly, Ah Wai not only stated the importance of individual situation and needs but also commented on the medical experts. He brought out the point that "they are not users, so they are theory-oriented." And he further highlighted that different physical conditions of the impaired led the professionals to make wrong advice. He claimed that "Actually they would not try to sit on it to experience the sensory feeling. As they are not impaired, they don't really know the problem."

In addition, Ah Wai pinpointed the role and relation between the impaired people and medical experts in a specific way. He proposed that "you need to understand impairments more. But if you wants to get more information, and you have to depend on the experts." Ah Wai's view was that knowing more the effect of impairments is through more contact with the people with impairments. The experts did not have the first person experience and therefore at best played the role of informant rather than authority. In other words, experts should listen to their patients to understand impairment effects rather than drawing on bio-medical knowledge to make sense of the clients' personal experience.

Ah Wai's lived experiences provided a solid foundation for understanding the physical problems. On the one hand this foundation established the trial and error process, and on the other it closely referred to the impaired people's personal situation. Ah Wai's capability, which was enough to handle the problems he encountered, seems not to have come from the help of the experts, but was a result of his direct embodied experiences. He used less expensive cushion as an example to support his point of different solution to different individual situation and needs. He said in the interview that "but I've some experiences of sitting on some cheaper one. I'm used to sitting on Sea Horse." He made use of his case to testify and challenge the theory and judgment of the medical practitioners.

To locate the role and position of the impaired people and the experts in health keeping, Ah Wai clearly identified the experts as supportive and secondary to the impaired people. The experts were regarded as an informant for collecting rehabilitation information on account of the fact that they lacked a deep understanding of the impaired. As compared with the experts, he stressed on the importance of the feeling of self. He explained that everybody had his/her own needs. Hence, people must pay attention to the most suitable way to deal with the needs of people with impairments in accordance with each individual situation and physical conditions. At the same time, he encouraged the impaired people to participate in the associations of the impaired which would benefit them in keeping contact with more impaired people, and thus they could understand the issues about rehabilitation more thoroughly through sharing.

We can see the Ah Wai's counter-narrative to medical discourse. Although medical discourse seems to be authoritative, people with impairments, like Ah Wai, would find it too universalistic and needed to be modified. According to the handbook of Prevention and Management of Pressure Sores, which was published by Rehab Aid Society Ltd., the impaired people should consult the experts in choosing appropriate cushion rather than making the decision by themselves. The handbook wrote that "it is extremely important to consult a professional and obtain a cushion prescription, as many factors are taken into consideration for choosing the most appropriate pressure relief cushion for your needs. There are advantages and disadvantages of each type and one could actually contribute to pressure sores if the cushion is not suitable for you" (1995:16). According to the handbook, professionals are the critical people in choosing appropriate cushion for pressure sores as they have such professional knowledge. However, Ah Wai criticized such professional knowledge as theory-oriented without actual experiences as backup and its value was thus limited. He further affirmed that the first and the most important thing in understanding and handling their body condition were the impaired people themselves. The questions of refusal of medical domination in the rehabilitation process and the significance of individual embodied experiences and their sharing among the impaired were raised in this case. Ah Wai affirmed his way and refused to follow the guidelines suggested by the dominant bio-medical discourse. Finally, he constructed his own way in health keeping and in dealing with his daily life matters.

Case 3

Ah Tung, a man in his forties with quadratic impairment, was living with his wife and a domestic helper in public housing estate. He had been injured in a driving accident more than ten years before. For ten years, he had stayed in different hospitals for medical treatment and rehabilitation training. At the time of interview, due to his severe injury, his helper did most of the caring jobs. Ah Tung said that his health condition had deteriorated gradually recently. He had undergone an operation to cure his bladder infection several days before the interview. However, in face of his poor health condition, he responded to it with his experiences and awareness in tackling such problems. The following transcript records his responses:

Ah Tung: Cold will become much colder. Why do I say so? It is because our nerves are damaged. When we sense it is cold, it is actually very cold.

Interviewer: Only a short period?

Ah Tung: We need a warm blanket to cover ourselves all over. It is not surprise to wrap us up for an hour. The aim of doing so is to raise our body temperature again. However, if the weather is hot, we may be nolonger able to tolerate that temperature either. Then you will need water spray, fan or air-conditioning, otherwise it might lead to heatstroke. As to my case, I am in trouble because I am different from the normal people. As I cannot sweat and the lower part of my body cannot regulate the temperature automatically, I have to take care of myself. When I am in the open air, I have to bring with me water sprayer and fan. Also, I will avoid going out when it is very hot.

Ah Tung: We are inconvenient people. Some of us use the catheter all the time. It looks like a condom. But sometime the urine still leaks out from it. Over the past two years my illness has undergone a long process and become complicated. The catheter causes inflammation and it would make the kidney get worse. In addition, it makes us difficult to piss. It affects the kidney. I've done so many surgeries these days. In the latest one, it was discovered that my bladder was atrophied. Thus my kidney suffered. Several days ago, I had a surgery to link one part of my large gut to the bladder in order to enlarge the latter. Then, a hole was made beside the navel so that the bladder is inundated regularly to channel the urine out of the body. It is good as ……, it is effective to release the pressure. Indeed, it is necessary to be inundated per several hours. To my case, it affects my bowel movement and it is necessary to use medicine to facilitate evacuation. There are advantage and disadvantage. To the former, it can control the evacuation time (we can evacuate once per two or three days) so that we do not have to worry about the uncontrollable evacuation when we are out. However, to some other specific body situations, i.e. to those who cannot move by themselves, it is necessary to seek help from others.

He also understood the importance of knowing his conditions. Impairments caused many complications. He spent a lot of time on doing exercises to maintain his health. Good health is an essential indicator for him to live with a good life. Certainly impairments always affects his 'being' in the sense that, if he is able to keep good his health, he has an image of a capable person.

Interviewer: Is it true that quadratic impairment would likely to get injury?

Ah Tung: When your body is not capable of moving, the blood circulation would get worse. Just like those people in lack of exercise, your cholesterol would be at a high level and your metabolism will become poor. In that case, you may be infected easily. You may know how to train up yourself or do more breathing exercises. You are advised to eat more vegetables and fruits with a reasonable portion of meat. Low pressure in life is needed. Good sleeping is also a good way even for normal people. Catching cold is an individual case only. Therefore, someone suggested that if western medicine renders no obvious effect, people might look for Chinese Herbalists to improve their physical condition. If you cannot maintain your health in good condition, the theory of "blood and energy" pinpointed by Chinese Herbalists may be helpful to you.

Ah Tung always maintained a good awareness of his being, i.e. the sense of his body, and he also understood it in detail. He knew quite well his body's response to cold and hot, the difference between the common people and the impaired and what the normal standards were. He could clearly articulate his kidney and bladder trouble and the advantage and disadvantage of surgical operation. Moreover, Ah Tung held a positive attitude towards his physical problems.

Interviewer: Is it possible to use your experience to face your disease?

Ah Tung	Certainly. Worry makes people aware of taking preventive measures. When we know this is risky, we will try to prevent it from getting worse. So, I think this is a good "worry". Let me tell you a case. Two years ago, our member Mr. Leung vomited and couldn't eat anything. His case was very serious. We took him to Cheung Chow hospital. The doctor said he was all right. The next day, he fell ill again. We sent him to the hospital again. This time the doctor said it might be a gut problem and he should be transferred to Queen Mary Hospital. However, there was still no result after computer scanning. Several days after, it was found that he suffered from an inflammation of his bladder. Finally, they used some kind of tube to release the liquid of the blains inside. It was a nasty smell!

As far as physical problems were concerned, he did not deny his worry. However, he treated his worry and risk of health problems in a positive way. He declared "worry makes people aware of taking preventive measures." He reacted to risk with confidence. To Ah Tung, knowing of risk meant knowing how to take preventive measures. This attitude made him free from dominance of the conventional notion of risk in health.

Furthermore, in the relation of medical experts and the impaired people in rehabilitation process, the opinion of Ah Tung was similar to Ah Wai of case 2, which we had discussed previously. He made comments on the issue of experts' advice similar to those put forward by Ah Wai. The following transcript illustrates this point:

Ah Tung	He wouldn't listen to our explanation why the condition of your buttocks would deteriorate. He would first blame you for always sleeping on the bed. Actually we understood where the problem was. Though we bought a cushion worth at 10-20 dollars, it could

still prevent us from getting bedsore. On the other hand, some people even bought an expensive cushion, but they still had bedsore. There's no cushion that can prevent you from getting bedsore. It just depends on how you use it. Once I got bedsore, I would replace the old cushion with a new one and clean the wound. Life is like that.

Interviewer: They said Sea Horse...

Ah Tung They said that it doesn't work. It takes time to recover. They said if you keep using Sea Horse, there would be chances to get bedsore. Actually they have no experiences in using the cushions. Their comments just brought humiliation upon the patients. Patients should try to use various kinds of cushions to see which kind was suitable for them. Practically, there are many medical staffs who do not really understand the patients.

Ah Tung Those medical staffs always just commented on the case in general instead of dealing with it specifically. For example, somebody had bedsore on somewhere between his buttock and his thigh. The condition of his caudal had deteriorated too. You cannot generalize a unified rule from all the cases and just ask the patients to keep sitting and not to sleep so often. To find out the most comfortable and suitable living environment for each patient, it is communication between the patients and the medical staffs that counts. Each patient wants different living quality and condition, but many medical staffs just use their "professional point of view" to think how the patients should live. It goes without saying that they have learnt a lot in their respective disciplines. It remains a question whether those professional suggestions can be suited to the family conditions of the patients. I'm of the opinion that what is most important is communication between the two sides.

Ah Tung It seems that life experience is very important to treat the illness of each patient. I agree with this idea.

To response to the advice from the medical experts in choosing cushion, Ah Tung declared that "there's no cushion that can prevent you from getting bedsore. It just depends on how you use it". Medical staffs had no concrete experience in using cushion, that was the reason why they had limited understanding of the impaired people, and it was also the cause why they brought humiliation upon the impaired. In Ah Tung's view, the experts always generalized the situation. He claimed, "those medical staffs always just commented on the case in general instead of dealing with it specifically." With the power of knowledge in their hands, the medical experts probably often offer advice from their professional point of view. However, this professional view achieveed nothing except miscalculation of the needs of the impaired. To comment on this situation, Ah Tung pointed out that "it seems that life experience is very important to treat the illness of each patient."

In addition, Ah Tung highlighted two cases about himself and his friend, which showed the medical experts' ignorance of the impaired people. The following transcript tells us the story:

Ah Tung The doctor pressed my waist to check whether I got appendicitis. However, many disabled persons don't feel the pain, even though they got appendicitis. My case was like that.

Interviewer: Did you mean that the doctor should not apply the usual method to check you, for it was used to check the ordinary people, and that was why he made a wrong judgment?

Ah Tung Exactly!

Interviewer: You meant he should not check you by pressing your waist.

Ah Tung Yes. The disable people should tell the doctor if their waists are not sensible enough. But I dared not tell my doctor. Ah Tao was very lucky. He felt pain in his waist and had a fever for a week. The doctor checked his body with computer scanning and found out the inflamed part. We shared this case with our people who didn't get such kind of information from hospital.

In the first case, the physicians lacked experience in handling the case of the impaired people. They had no relevant experience for him to make reference in diagnosing the case. Therefore, although they had made an assessment for several times, they failed to draw a correct diagnostic conclusion.

In the second story, Ah Tung got appendicitis. The physician treated him with the usual practice, which neglected the fact that his waist had lost sensation and that he was a quadratic impaired person. This case revealed that there are different physical features between non-disabled people and the impaired. Doctors normally assume that body conditions of the common people are all the same and tend to take it as a universal standard. They understand the impaired people's behaviour pattern, logic of thinking and perception towards others on the basic of those of the non-disabled. The needs or features of the impaired have been thus ignored and marginalized.

To react to the above situation, Ah Tung suggested that the impaired people should make their physical features known to physicians and medical experts. Moreover, he was eager to share this experience with other impaired people in order that such a situation might be avoided.

Case 4

Fong, a female in her forties with lower limbs impairment, was living with a domestic helper in a public housing estate. Early this year, his husband, Yan, died of stoma cancer. In the past, her husband did most of their household affairs, as his health was better.

Fong mentioned two cases on health maintenance in her and her husband's lives. The first case related to her husband is as follows:

Fong: They may get pressure sore, which is not easily healed. My husband got pressure sore. He washed his sore by the community nursing service. However, his situation got worse a week later. The wound became larger. My husband decided to wash his sore by himself and so he rejected the community nursing service. The community nursing service requested my husband to sign up a document for cancelling the service. After a week, my husband healed the wound. That proved self-caring is better. The community nursing service would clean the sore only once a day, whereas my husband would clean up his sore whenever he needed. After showering, he could clean up his sore once again and even in the holidays.

Interviewer: Did you mean that the community nursing service didn't come in the holidays?

Fong: Yes.

Interviewer: You have mentioned that the community nursing service requested your husband to sign up a paper. Could you tell me about it more?

Fong: The community nursing service asked why my husband stopped their service. My husband told the nurse that when he lay down to check his wound with a mirror, he found that the situation became worse. So the nursing service was unable to help him.

Interviewer: How did the nursing service respond to your husband?

Fong: There was no response at all. The service didn't change its

> practice. Actually, it could do nothing to help my husband. My husband signed up a document declaring that he had cancelled the service. A doctor had introduced the community nursing service to my husband several years ago. My husband visited the doctor for regular consultation. He had cleaned up his sore by himself, but the doctor told him that the sore was not easily healed and so on. So my husband received the service.

The above case is about Yan, the husband of Fong, when he got bedsore. With the doctor's authoritative advice, Yan received the community nursing service in handling his bedsore problem. However, the situation got worse after a week, Yan decided to withdraw from the service. Then Yan was requested to explain the reason why he had to stop the service and sign up a document for the organization.

Fong gave further explanation of such a withdrawal decision. She explained that the limited service in handling the sore made the situation worsen. The service only visited her husband once a day and no service was available in the holidays. On the other hand, her husband could have more time to take care of the sore at home. He would clean up the sore two or more times a day. Thus, they believed that self-caring was better. In fact, service through a week's time did not achieve the desired result, but on the contrary, the condition became worse. Yan's decision to terminate the service was not only reasonable but also rational.

However, in the process of receiving the service from the community nursing service, it revealed the tension between medical practitioners and Yan, an impaired people, on how to manage the latter's health. When Yan attended regular medical consultation, the doctor told him about the difficulty in handling bedsore by himself. The doctor's medical authority implied that the impaired was unable to handle the situation and needed professional assistance. Professional knowledge and skill was regarded as more reliable than personal method. Finally, Yan was convinced to apply for the service of the community nursing service though he still believed that he could handle the problem by himself.

A week later, the bedsore got worse. Then he lost confidence in the service. Thus he tried to terminate the service. At this moment, the tension between the medical authority and him came up again. Yan was asked to give explanation of his termination of the service. Moreover, he needed to sign up a document to declare his withdrawal from the service by himself. These practices located the medical service recipient or the impaired under the health management and control. The role of service recipient was expected to follow the advice of the medical practitioners and to receive related service. This role requested the impaired people to shoulder both behavioural and moral responsibilities as a cooperative patient. That Yan asked for termination of the service by himself, rather than by recommendation from the medical practitioner, disrupted the existing social relation between he himself and the medical practitioner. According to the regulation, the termination of medical treatment is to a large extent based on the judgment of medical practitioners. Without medical practitioner's approval or consensus, the termination will be treated as irrational and a risky decision. Thus, Yan was requested to give explanation of his termination and to sign up a document in order to shoulder the responsibility of such termination. Yan was willing to bear the responsibility since he found the medical practitioners disregarded his own feeling.

Yan's action of terminating medical service showed his resistance to accepting unsatisfied medical service. Yan refused the medical power imposed on his impairment condition. He explored his own way of managing his physical problem effectively. This illustrated that he was the master of his body and person, as he understood his body more perfectly and deeply, as compared with the others. His act overthrew the constructed role and image of the impaired that had been constructed by medical professionals.

Fong also expressed similar opinion on inappropriate medical advice. She reported that 'usually, the doctor and nurse would suggest how much water you are to take. However, it is irrelevant. For people's bladder is small, and this would lead them to urinate too frequently. If their urine could not urinate completely, some urine would be left inside the body and so it would cause inflammation. So to have too much water could also lead to inflammation. This is our experience. Maybe this is not knowledge, but we know what we need' (Fong, interviewee).

There was advice for preventing inflammation by medical practitioners. Fong was taught to drink more water as a preventive way. However, she thought that such advice was inappropriate or even dangerous to her. Fong explained that poor urination was not suitable for drinking too much water. The advice of the professionals becomes inappropriate, for it does not put the characteristics of the impaired into consideration. Although the impaired people lacked professional knowledge, they understood themselves. She concluded that although her viewpoint might not be knowledge, she knew what she needed.

Lay knowledge and method of the impaired people coming from the lived and bodied experiences challenged the dominant and fixated ideology of the medical practitioners. Medical practitioners hold fast to the non-disabled's norm on the one hand, and on the other, generalize the impaired conditions as a whole and neglect the different aspects among different groups. Fong's complaint indicated that the medical practitioners offered advice on treating inflammation too general without taking into account the impaired condition. Fong's objection also showed that she rejected medical domination. She looked for her way of taking care of herself and affirmed the value of her lived experience on her impairment.

Case 5

Sheung was a wheelchair user for more than twenty years. At the time of the interview, she was living with her old mother in a public housing estate. With normal upper limbs, she and her mother managed to do most of the household work. She only asked for help from home help service when she needed house cleaning work, especially in the high places. In the past, she lived in a flat. As the lift did not reach her flat, she was thus isolated from public life for many years. After the removal, she was free from homebound since her flat was accessible by lift. From then on, she had actively participated in different organizations of people with impairments and joined their activities. Recently, her hands got worse. They had sensory problem. The following illustrates her worry:

Sheung: There was no such a problem. But now my hands appear to lose sensation.

Interviewer: Humph.

Sheung: If the problem becomes worse, I need to have an operation immediately. I hope in this way the (muscle) situation could be improved.

Interviewer: Hum... The situation could be improved?

Sheung: I will report the situation to the doctor in regular consultation next month. The orthopedics clinic. Now the problem has become more serious. The doctor asked me to be aware of the deterioration of my nerves. By then, operation will become useless. Such advice has made me feel confused. I don't know what's the appropriate time for the operation. Or too early?

Interviewer: Hum....

Sheung: I am afraid it is too early. I don't know whether it will become better or worse. Maybe it will become better. I worry that some side effects will occur after the operation. I worry about ...

Interviewer: Yes, I understand your situation.

Sheung: I don't know!

Interviewer: Will you clarify this question in the coming regular consultation?

Sheung: Yes, in the coming consultation.

Interviewer: Is the pain makes you worry? I mean will it make your daily life not so safe?

Sheung: Sure! I'm afraid it will become more and more serious. I always worry that all my limbs cannot move one day.

Interviewer: Hump...

Sheung: It is terrible to think that my arms become impaired. You know, my legs already cannot move now.

Interviewer: Humph...

Sheung: Sometimes, I feel I can hold things tightly, but actually it is not the case. Also, my reaction is so slow.

Interviewer: Do you suffer from some kind of paralysis?

Sheung: Yes! When I went to toilet, I thought I had held the handle, but actually I hadn't. When I used a wheelchair, one of my hands couldn't catch the wheel. All of a sudden, the wheelchair turned direction.

Interviewer: Is it seriously injured?

Sheung: Not very serious. No need to go to hospital. But there were a lot of accidents. Sometimes I had to think of home safety.

Interviewer: Have you thought of how to prevent?

Sheung: No, no use. Everyone said to me, "Be careful". However, when accident happened, I must be not on the alert. No way to exercise prevention.

Interviewer: Do you have the feeling of impending crisis?

Sheung: No. I don't think it is risky fatally. I will keep an eye on the surroundings. I just worry about the surgical operation. I worry about its result. I even think of the possibility of not performing the operation. Actually, I am strong enough to endure my pain. Sometimes there was no pain for a few days. I worry it will be too late for the operation if I wait. The nerve will die out.

For Sheung, the problem in the sensation of her hands brought her anxiety. The problem of sensation had not heightened her vigilance on risk in daily life. She believed that she could handle the situation with her body coordination – hand-eye coordination. Therefore, she answered this question with confidence. The response of Sheung was quite unexpected. The degree of impairment is taken as a major reference for assessing accident occurrence. It is believed that the degree of impairment reflected the degree of the probability of accident occurrence. Since the condition of her hands had deteriorated, Sheung became more worried about getting accident or injury. However, she determined to handle her situation with better body coordination. Her worry did not seem to come from her life management but rather from the external factor – the surgical operation.

According to the doctor's assessment, she needed to undergo an operation because her nerves were deteriorating. When the nerves deteriorated, her hands would not function properly. The assessment and the possibility of failure in the operation caused great anxiety in Sheung. The assessment showed that she would become quadratic impairment in future if the nerves had deteriorated. To Sheung, it was a tragedy to become quadratic. She wished to improve her condition through surgical operation. However, the uncertainty of timing and the degree of success of the operation confused her. These questions were difficult for her to make up her mind. Again, we see the 'being' of people with impairment affected by impairments. This shows the importance of impairments to the lived experience of a person with impairments.

Nevertheless, the involvement of medical practitioners has impacts on one's feeling. The question of this case, in fact, was the medical uncertainty. Sheung had not been told what time was most suitable for the operation and what consequences would arise in the operation. Medical experts and knowledge provided insecurity to her problem rather than solving it. Medical assessment only delivered negative message to her situation. Sheung, as a common person, worried about her physical deterioration. However, such worry was to a great extent created by medical uncertainty. This uncertainty placed the responsibility onto Sheung. Sheung shouldered the responsibility imposed on her by the medical practitioners.

In the former discussion, it was revealed that Sheung was filled with confidence in handling her life with hand-eye coordination and in facing the deterioration. And she was strong enough to endure the pain in her hand. Thus, we may say that she was capable of handling her life and herself, but it was difficult for her to share the problem originated from medical uncertainty. This uncertainty went hand in hand with Sheung's management of her health, and then the problem was transferred to the one stated in terms of bio-social nature. The possibility for Sheung to handle the uncertainty was limited. She was intended to bring forth this question to the doctor for discussion again in the next regular consultation. It might be the right way for her to ask for more concrete medical advice.

Summary

I have discussed five cases in this chapter. In these cases, we found that physical conditions and family backgrounds of the people with impairment constitute a specific situation that a person with impairments has to figure out particular strategies to deal with. Through our discussion of these cases, we know the interaction between the impaired people and the medical practitioners, and how medical practitioners exercise their professional authority upon the impaired. We also understand how the impaired people insist on using their personal experience to construct their lives.

In the story of Lan, the young lady, she faced her physical deterioration, which would lower her movement ability. She knew that medical treatment was of little help to her condition and thereby made use of her general health maintenance knowledge, such as nutritious food, more sports activities, being happy and sharing with others, to train herself up. She wanted to show how active the impaired people were through social contacts in public areas. Such attempts lead us to understand that Lan was trying to create a positive image and identity for her and was ready to act out in public.

In the case of Ah Wai, he got injured a long time ago and thus had accumulated rich experiences in handling physical problems. Limited mobility and loss of sensation had not lessened his ability to manage physical problems. He pointed out that what importance of the impaired people's feeling in health keeping and that practical experiences of the impaired could provide more concrete and direct references for selecting appropriate methods and equipment. Ah Wai showed confidence in managing his physical problems.

Ah Tung had rich experience in handling his health problem. He also shared Ah Wai's view on the importance of lived experience. He particularly mentioned the gap in cognitive mapping between the medical professions and the impaired. The professionals stuck to the norms set by non-disabled while impaired people take action to resist and challenge such situation in order to make a change.

Fong was a wheelchair user for more than thirty years. She lost her husband, Yan who got stomach cancer and died in 2002. Both had experiences in struggling with the dominance of medical practitioners in the rehabilitation process. While Yan asked for termination of the service provided by the nursing service, medical practitioners regarded his request as irrational and unreasonable. This illustrates how little space for the impaired people to enjoy self-determination. Yan insisted on adopting his own way to replace the existing practice in the rehabilitation process. We have learnt from this situation that the fluctuation of the psycho-emotional state of the people with impairments who were involved in struggle, was related to their body condition and outside factors, as there existed the service provision mode in which the doctor 's recommendation played an important role.

Fong, in her case of inflammation, rejected the nurse's advice of drinking too much water. She criticized such advice as neglecting her specific physical condition. She argued that those impaired people with poor urination function were unfit to drink too much water, for the urine would be heavily accumulated in the bladder that might cause inflammation in the end. Similar to Ah Tung's case, here showed the medical practitioners' neglect of the physical difference between the non-disabled and the impaired. Fong clearly admitted his lack of medical knowledge but she knew what she needed. She refused to take the advice and avoid becoming a conformist to medical authority.

Sheung was the last case in this chapter. She was wheelchair bound, and remained an active member of a number of associations for the impaired. she got sensory problem in her hands. Several minor home accidents occurred. She worried whether the result of the surgical operation could solve her problem or not. The doctor did not give a definite reply. The deterioration of her hands brought anxiety to Sheung, for she feared of becoming a quadratic impaired person. She felt puzzled whether the surgical operation was performed at the right time and whether its result would bring any positive result, as the medical practitioner did not give her a definite answer about it. Under such situation, Sheung could not make up her mind. We know that impairment problem and medical uncertainty came together in this case and resulted in her confusion. She could handle the deterioration condition of her hands with better hand-eye coordination, but it was difficult for her to solve the problem of medical uncertainty.

In this chapter I have tried to explore the impairment effects and its psycho-emotional impacts on disability through five cases. We look at the lived experiences of people with impairments in order to reveal the interaction of impairment effect and disability. In these cases, I presented what medical practitioners had done, how the impaired reacted and what alternative or counter narration was brought forth by the people with impairments. I want to elaborate the above scenarios to enable us to understand what and how social struggle takes place.

In health maintenance aspect, the interviewees tried their best to keep their physical condition though medical service could be of little help. They had not regarded this medical judgment as something dominating their fate. The interviewees had their own ways to react to medical judgment. Eating nutritious food, doing more exercise and better hand-eye coordination were their methods adopted to handle their body state. The role of passive victim had not been established in the interaction with medical practitioners. In contrast, they made use of what they had or could use to handle their problems. I do not say that worries had not dampened the interviewees' will to overcome their difficulties. Worries did exist. The question is how people with impairment reacted to such worries. They solved their problems in their own ways, even if they encountered difficulties and felt frustrated. In the five cases, we can see that medical uncertainty and failure had not thwarted the interviewees. They managed to act as an active agency to negotiate with the situation. Physical impairment and medical ineffectiveness has not placed them onto the victim role and tragic lives. On the contrary, people with impairments showed how they insisted on resisting bio-medical domination.

On the other hand, our interviews also disclosed the question of how medical practices dominated and marginalized the impaired health condition. The medical practitioners such as experts or professionals seemed to know little of the impaired condition. The case about bladder inflammation illustrates how medical practitioners were unfamiliar with the impaired body. The practitioners had to spend several days in finding out the inflammation in the bladder. This example indicates that the practitioners had little idea of the impaired body. Owing to their unfamiliarity, they were difficult to distinguish the difference and features of the impaired body as compared with the common one. In other cases of body examination, some interviewees commented that medical practitioners often generalized their cases rather than treating them as particular individual cases. Such practices included two types of approaches. The first one is to put the ableist norms upon the impaired, which applied "general practice" for normal people to the impaired. The second one is to treat all the impaired medical cases in the same way without discrimination. These two approaches were criticized as useless for treatment. These approaches were imbued with social prejudice to the impaired. The impaired body was rejected in line with the cultural level in societies. Thus, society set social barriers between the non-disabled and the impaired. The impaired body is barred from having contact with the public. Owing to such social boundary setting, the impaired body becomes unfamiliar, unusual and even strange to the non-disabled. The consequences of such cultural block, the non-disabled people, even the professionals – medical practitioners, know very little of the impaired body. It reveals that the impairment issue is not only a matter of individual practice between medical practitioner and the people with impairment but it is also related to a wider socio-cultural aspect.

- End -

Chapter 6

Conclusion

This chapter includes four sections. The first section is a summary of findings of this study. The second section is about the theoretical implications of this study and the third section is on the significances and shortcomings of this study. The fourth is about the possible scope for further study and policy implications.

I. Summary of findings

The objectives of this study are four-fold. The first aim of this study is to examine how social inequality, which is measured in terms of spatial, temporal and social dimensions, against disabled people is socially constructed in Hong Kong. We concern with the construction of social inequality by professional and laymen practices. The second aim is to explore the extent to which risk management shapes and effects the construction of disability in Hong Kong society. I give specific attention to the interactive relations between social practices and risk management in the process of social construction of disability. The third aim is to examine the psycho-emotional dimensions of disability and impairments prevailing among people with impairments, an aspect of disability that a feminist disability researcher Thomas emphasized. This is related to our fourth aim, that is, empirically applying the concepts psycho-emotional dimensions of disability to the study of disability in Hong Kong. This is to explore the extent to which people with impairments, in face of socially imposed restrictions, are able to resist against the dominance of bio-medical practices and the social discriminatory practices in their daily life.

In Chapter two, I have shown the foundation of individual/medical model that is laid on physical functioning towards people. Disability, in this view, is a tragedy of personal affair. In contrast, in order to overturn the dominance of individual/medical model on disability, social modellists have shed light on social environment and see its effects in the creation of disability. In this model, social situation has been traced as the origin of disability. In order to enhance the applicability of this model, I employ the concept of risk management as a middle range concept to examine the construction of disability. The concept of risk provides insights for us into the issue as to how impairments are transformed into disability.

Furthermore, apart from these models, Thomas (1998) urged us to focus on the issue of psycho-emotional dimension of disability. She criticized that there are little efforts on the study of the psycho-emotional dimensions of people with impairments in the conventional social model. Hence, this study is basically informed by Thomas' model as stated in Chapter two.

In Chapter three, the issue of the management of disabled population is discussed. People with impairments are looked upon as the 'other' or being regarded as 'abnormal'. In modern society, rational control and management are taken as an effective means to maintain social order. People with impairment are imposed with negative image as 'other' or 'abnormal', thus they become the targets under management in society. Strategies of public control and the promotion of self-management of people with impairments are interrelated. Three various domains including medical setting, public setting and the private home are illustrated for looking into the life of people with impairments on negotiation of their subjectivity.

In this chapter, I also argued that wheelchair users, just like any other people with 'visible' impairment, found it more demanding for them to accomplish independent living since the visibility of their impairment under public gaze has already put them in a less equal social position. Living in modern societies where independence is appraised as the essential capacity of human beings, each individual knows personal performative capacities are at a premium and should make them visible to others. This is the strategy for individuals to gain their proper position of citizenship in modern societies. However, with the common belief that people with impairment are vulnerable to modern urban life, common people would categorize them as the 'Other', showing them sympathy or discriminating against them. Our findings show that in Hong Kong where individualism prevails and the lack of the sense of community is prominent, the bodies of the people with impairment have been marked by a script that individuals should be responsible for the management of the risks being encountered in their daily life. Therefore, people with impairment should learn how to exercise self-care and be responsible for any problems arising from their daily life. In the medical setting, despite the dominance of medical explanation and knowledge about the causes of physical impairment, the doctors seem to take self-reporting as the most suitable method of diagnosis. The authoritative medical scripts are out of the hands of the people with impairment and so it is not easy for them to report clearly their subjective feelings and physical state to the doctors. While the self-help guideline stresses that the inner bodily world of the patients is under the responsibility domain of medical practitioners and that part of the body has been cut off from the intellect of the patients, the doctors request the patients to report the state of the inner part. This resulted in an ironic situation. When the issue is understood as a personal decision on whether one is to attend regular medical checkup. People with impairment have an idea that on the one hand one is responsible for one's body, and on the other one should bear the cost incurring from the risk of not attending regular medical checkup.

The issue of risk also comes into view in the everyday life of people with visible impairments. This is a common issue in the use of public transport. Wheelchair needs more space and the wheelchair users need more time to get on the bus but people thought of it as time-consuming and not fit the temporality of modern societies. Our interviewee seemed to be unable to counteract this idea and therefore they preferred to wait for a long time for a bus with a ramp. They seldom made complaints.

While people with impairments show strong willingness to take risk, the people who are supposedly responsible for protecting and promoting the well being of citizens show an opposite tendency. As has been argued, it is perhaps because of the lack of discussion on the exclusive nature of the built environment in Hong Kong, public safety agencies have few guidelines for them to follow in the case of offering assistance to people with impairments. Taxi drivers worry that offering help in lifting wheelchair would bring them injury and therefore are reluctant to take such risks; policemen have the same worry and back out even if they found a wheelchair user unable to go home when elevator was out of order. Security guards attempted to shift the burden to the police in order to avoid taking any risks. This social attitude has become a barrier against the effort of people with impairment to try to be geographically mobile. This kind of attitude not only discourages people with impairment from going out to realize their rights to social participation, but also helps people with impairments foster the idea that they should confine themselves within their private homes. When personal living space is designated as the most safe and suitable place for people with impairments to stay, and the occupational therapists and physiotherapists put much efforts on improving the interior design for people with impairments, disability is created and reproduced. Unless the built environment has been designed in an inclusive way and the public is willing to share the responsibility of taking risks, people with impairments will remain trapped in their private world. This is really a situation in which physical impairment is translated into disability.

In Chapter four, I brought the human agency back into the study of disability. I paid more attention to the psycho-emotional dimension of disability, as that which put forward by Thomas (1998). The focus of this approach draws our concern to (i) what the impaired people do, (ii) how they act (are prevented from doing and acting) as disabled people, (iii) who they are (are prevented from being), and how they feel and think about themselves. These concerns help us to understand how the practices of non-disabled undermines the psychological and emotional well-being of people with impairments, which is called 'internalized oppression' by disabled activists.

In spite of focusing only on wheel-chair users, I have illustrated the 'sameness' or the 'shared features' of disabled and non-disabled people's lives as a whole. In our case study, many interviewees did encounter the dominance of professionals and the appalling outcomes of strict bureaucratic attitudes. There was little room for manoeuvre for the people with impairments to negotiate with the professionals. In fact, in modern societies, bureaucratic ruling spreads over different domains and thus, under the surveillance of professionals and bureaucrats, neither disabled people nor non-disabled people could enjoy independence and reasonable provision of social services. This reflects the ordinariness of the socio-economically disadvantaged people. Of course, apart from the general problems in ordinary life, people with impairments experienced a particular process of exclusion that results in disability. Their sense of being is then affected. Many interviewees in this study felt upset and confused about her ability in managing their own daily life, and sometimes felt powerless and vulnerable to bureaucratic intrusions. Although they did attempt to challenge the overwhelmingly bureaucratic institutions that restrict their mobility ability and affect their well-being, people with impairments remained marginalized and subject to various forms of social restrictions. Nonetheless, the interviewees enriched their lives within the domain where they could control. Despite physical impairments, an interviewee's husband (a disabled too) played the carer role, contributing emotion and efforts to the well being of her. He formed his self-identity as a worthy person, and denied to be a 'passive victim' of oppression.

In Chapter five, with the discussion on the findings from five interviews, I illustrated that physical conditions and family backgrounds of the people with impairment constitute a specific situation with that a person with impairments has to figure out particular strategies to deal. I presented the interaction between the impaired people and the medical practitioners and focused on how medical practitioners exercised their professional authority upon the impaired. What I focused in this chapter is however not about the dominance of the professionals but on the ways through which the impairment effects on the impaired people were neglected. I found that when medical treatment was of little help to the their condition, the interviewees made use of their general health maintenance knowledge to train up themselves. Another interviewee's experience shows that the impaired people's knowledge of health keeping and their practical experiences of the impairments provided concrete and direct references for selecting appropriate methods and equipment. They were aware of the gap in cognitive mapping between the medical professions and the impaired. While the professionals stuck to the norms set by non-disabled, the impaired people take action to resist and challenge such situation in order to make a change. I explored the impairment effects and its psycho-emotional impacts on disability through cases. I look at the lived experiences of people with impairments in order to reveal the interaction of impairment effect and disability. In these cases, I illustrated what medical practitioners had done, how the impaired reacted and what alternative or counter narration was brought forth by the people with impairments. I depicted the scenarios to enable us to understand what and how social struggle takes place. I argued that impairments are 'real' in the sense that that kind of physiological features of human being really brought negative feelings to the impaired people, regardless of the availability of social restrictions. Given that there was the ignorance of these impairment effects, disability is then created. However, what I want to point out is that our interviewees were not willing to take the role of passive victim, especially in the interaction process with medical practitioners. In contrast, they made use of what they had or could use to handle their problems. I do not say that impairments had not dampened the interviewees' will to overcome their difficulties, but I highlighted the fact that they could solve their problems in their own ways, even if they encountered difficulties and felt frustrated. In the five cases in this chapter, we can see that the people with impairments managed to act as an active agency to negotiate with the situation. Physical impairment and medical ineffectiveness have not placed them onto the victim role and tragic lives. On the contrary, people with impairments showed how they insisted on resisting bio-medical domination.

II. Theoretical implications

The studies of disability are polarized in the past. Medical model versus social model represents the crux in the problem of understanding disability. These models situate the nature and origin of disability issue on different foundation. However, both of them are criticized as making theoretical inadequacy and limitation. Corker and Shakespeare (2002) pointed out: "We believe that existing theories of disability – both radical and mainstream – are no longer adequate. Both the medical model and the social model seek to explain disability universally, and end up creating totalizing, meta-historical narratives that exclude important dimensions of disabled people's lives and of their knowledge" (2002:15). To Corker and Shakespeare, medical model and social model provide too grand a theoretical analysis, which are inadequate to understand the lives of the impaired. Moreover, the models are also too united to take into account the complex experiences of impaired people in the world. Unitary character of models excludes the difference and unique lived and embodied experience of people. These limitations imply that contextual or situated study on disability is needed to capture the complex situation and in turn to inform or challenge the mainstream theory.

For my view, I share the view of Corker and Shakespeare. I doubt the meta-theory to disability studies that is said to be feasible in capturing the issues about disability in an in-depth way. Having accepted the critiques of social model of disability, I borrow the ideas from Carol Thomas and developed a framework to study the psycho-emotional dimensions of disability and impairments to approach the psychological and emotional issues of disability. From that, she provided us a theoretical framework to take into account personal experience and feeling towards disability and impairment. The interaction of impairment effect and disability contributes to the formation of the lived experiences of people with impairments. Such experiences are in fact the feeling, roles and identity of people with impairments. This lived experience represents the encountering of outer and inner world for people as a holistic entity rather than as a separated one. People with impairments should not be counted in what they functioned or limited, as doing, but neglect what they felt, as being. Personal feelings or embodied experiences play a vital part in human being that lay foundation for understanding and interpreting of self. Hence, to have a better understanding of disability and impairment, attention should be paid to in-depth lived and embodied experiences of impairment and their interactions to wider socio-structural and cultural context.

To put the above concern into practice, in this study, I both locate the issue at societal level to examine the strategy risk management on the disabled population and investigate the aspects of psycho-dimensions of disability and impairment of those people with impairments. The situated and contextual narratives on impairment were illustrated in this study. In sum, the macro level of management of population and micro level of daily interaction has been analyzed in this study. This also shows the interaction between social systems and agency (the impaired), and how (the extent or form) the agency acts out his resistance to the situation.

III. Significance of this study and limitations

In Hong Kong, although there are more concerns about the issue of discrimination against disability, the issue of social construction of disability is still excluded from social agenda. In comparison with the voluminous research conducted foreign countries, there were only a few efforts on the theoretical development and empirical investigation on disability in Hong Kong. On the other hand, despite of the fact that professionals, such as the doctor, physiotherapist, occupational therapist and social worker, play a critical role as case managers for the impaired to manage their welfare, the perspective of professionals has rarely been questioned. As a result, I found the dominance of the bio-medical discourses and knowledge.

The assessment and diagnosis tools employed by the professionals are seldom subject to public scrutinization. I maintain that professionals overlook their roles and positions in the proliferation of disability. The interaction between professional and the impaired in the process of service provision must be the major area for investigation.

In reviewing the studies of disability in Hong Kong, in social aspect, most of the studies dwell on the areas relating to service need and public attitude towards people with impairment. Only a few of the studies put emphasis on the social restrictions upon the impaired. Through this study, I expect to show that people as human being should be understood in a holistic way. We not only understand what they do, how they act/react, but also how they think about the situation and themselves. In the exploration of people's experience, we link our understanding of disability as well as impairments to the socio-structural and cultural contexts. Such an attempt is seldom seen in the disability study in Hong Kong.

Of course, there are a number of shortcomings in this study. The interviewer found him not sensitive enough to ask good follow-up questions to sort out personal feelings from the interviewees. Many issues were neglected. For example, regarding occupational therapy training, I asked how the interviewees improved their health but without asking him what they feel and how they act. Moreover, I found it difficult to interview the medical practitioners who used to refuse to attend interviews. The views of medical practitioners and professionals would provide us with more concrete information to validate if the dominance of bio-medical knowledge prevails.

Secondly, the duration of time for the interviews is too long. It took 12 months to complete twenty cases. After the first round of cases, I needed to modify my plan and about three months had passed. Later, due to personal reason as well as the alteration of interview arrangements, the progress of interview was thus delayed. At the end, late arrangement lead to insufficient time to make contact with more female interviewees, resulting in an imbalance of male and female in the interview cases, i.e. 15 male and only 5 female. I certainly agree that a feminist perspective would draw out attention to the social exclusion constituted in terms of gender.

Using narrative approach in handling the interviews, I teased out some plots and scenarios from transcripts. Owing to the length of chapter, it is impossible to record down all personal accounts in the text. Another reason of selection of narrative materials is the inarticulation of individual interviewees due to his/her communication patterns and their rejection of taking MD recording. The last but not the least reason is a question of representation. Some personal accounts, are more clear and complete in response for the major concerns of this study, are selected. In the process of editing, only a few plots and scenarios were selected but other possible plots were left behind. It is no doubt that a lot of valuable sharing in the interviews has not been put into analysis. To a large extent, I did not exhaust all the possible aspects inherent in the interviews. It is regrettable to see that while the interviewees show great enthusiasm in expressing their painful experience and feelings in interviews, I could not let their voices out in a total form through this study.

In addition, according to the framework of psycho-emotional dimension of disability, we need to dig out the issue in deep. Qualitative method and narrative approach has been adopted as the powerful and suitable research methodology. Both the theoretical framework and methodology assume people as an active human being and capable to articulate their live experience and feeling. However, is that true? As I have mentioned in previous chapter in explaining the criterion on selection of personal accounts, some interviewees are not easy or incapable to express their feelings and organise their experiences. Furthermore, single type of interviewee (wheel-chair users only) and 'one-shot' interviewing arrangement also pose a constraint to the scope of this study.

IV. Scope for future study and policy implications

For the researchers of disability studies, especially for the social modellists, research is criticized as being an inherent political nature. Disability research should adopt emancipatory purpose, which avoids the manipulation by the researcher. As Ngai (2001) claimed that "this does mean that the social relations of research production do have fundamentally changed; researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose". In other words, the central role of researcher should be turned to be the researched. The needs, orientation and objectives of the researched should be put in the research as the determinant factor. Such proposal increases or strengthens the participation and role of the researched a lot and ensures that the research project is fit for the need of the impaired. But, as Corker and Shakespeare warned us that "the notion of emancipatory research suggests that social investigators need to place themselves at the service of disabled people's organizations, and conduct research according to political priorities. This is not always seen to be compatible with research that is based on intellectual interests or instincts and that has the intention of advancing the collective interests of disabled people, however they might be defined" (Corker and Shakespeare 2002:14). This brings an old question into view, about the possibility of neutrality in conducting research. Moreover, as the researcher is a non-disabled, how could a non-disabled understand the feelings and experiences of impairments and disability? Obviously, the above issues alert us to be aware of the emphasis of collective interests and political orientation of the researcher. At the same time, the authoritative and dominant role of the researcher and funding body should be lessened in the process of study and delegate the decision power to the researched. From the development of theoretical framework of disability, medical/individual model, social model and psycho-emotional dimension approach provide us with different angles and origin to understand the issue. On the other hand, race, gender, class and social context, weave a matrix or texture for us to know the dynamic relation in shaping disability in society. For qualitative research especially, stresses on digging out the issue in deep level and broadening our understanding within the complex relations and factors towards the issue. Treating the researched as a subject, who interacts with the researcher actively and closely, leads to generate more insights and interactions to the study. However, on the other hand, we do need to avoid the doctrine that reliability and validity of research depends on single factor such as physical condition or form of body of the researcher. Form of body neither provides us with an absolute answer nor becomes a self-evidence of disability. Though body is a site of social discourse of disability and borrows the routine experiences of the disabled, cannot help us to understand the whole picture by such single condition. As I discuss in previous part, no united factor or meta-theory is satisfactory in understanding disability. For the framework of psycho-emotional dimension of disability, we should turn to looking for both impairment effect for individual and socio-cultural impact on disability. Apart from this issues, I want to emphasized that, on account of limited efforts on disability study in Hong Kong, any new attempt would bring us insights into the lives and inner worlds of people with impairments and the findings, would reveal more about the hardships and difficulties arising from the social imposition of restrictions on people with impairments.

In addition, the interviews also disclosed the inadequacy of regular medical consultation towards health maintenance and treatment of illness. Many interviewees did complaint about the uselessness of regular medical consultation. They pointed out that regular attendance just led doctor and medical bureau to know that they are still alive. Such regular consultation is nothing but a mechanism of management of disabled population. In fact, the cases illustrated the ways in where the medical professions are incapable of helping the disabled to solve their physical problems. Regular medical consultation does not serve the purpose of medical treatment and health maintenance but is itself a management process. Indeed, the management of disabled population in such medical consultations often overwhelmed the original task of health maintenance. For policy improvement, the guideline of the consultation should be made for the medical professions to shoulder responsibility to help the disabled actively. And, the disabled should be treated as human beings instead of just being regarded as 'medical cases' during regular consultation.

Moreover, in this study also points out the existence of various social barriers which in kinds of spatial, temporal and social. The Discrimination Ordinance of course, to certain extent, protects the right of the disabled in legal aspect. However, the cases in this study showed that the problems originated from a deep level, ie, in the daily lives of the disabled. Especially, the barriers and oppressions have generated in the process of risk management. People as the responsible actors will shift their obligations to the disabled when facing risk. Environmental friendly and improvement with no doubt benefit to the issue but the works to change people's attitude and culture, and mechanism for complaint are more crucial. The government should work hand in hand with the organizations for the disabled to improve the situation. With reference to foreign experiences, as quota system of employment, barriers free town planning, affirmative actions in social welfare, inclusive education for schooling and financial support for carer, are not only enhancing the betterment of the disabled but also changes social value and attitude towards the disabled and disability.

- End -

Appendix 1

Interview Guideline

1. **Physical condition:** long-term illness, mentally retarded, mental illness, organs, visually impaired, deaf and physically impaired, etc.

2. **Family background:** family members, relationship with the families.

3. **Cause of disabled:** congenital, after birth illness, after birth injuries.

4. **The feeling after injured/ having illness:**
-your feeling when you first got injured/ had illness.
-your feeling now,

5. **Daily life:**
-the arrangement of daily diet, schooling, employment and life, etc.
-the main point about the arrangements: order, number, frequency, method, pattern.
-the perception, principle, purpose or reason affecting the arrangements.
-the importance of the perception, principle, purpose or reason mentioned above.
-the social environment/ conditions related to the perception mentioned above.
-the problems aroused or change if you do not arrange your daily life according to the perception, principle, purpose or reason mentioned above.
-how will you arrange your daily life if you can do so arbitrarily? And why?

6. **The rehabilitative therapy, training and services received in the past and now:**
-what are the services?
-the effect/ need of the services you mentioned above.
-what are the reasons?
-the attitude you believe the medical staffs should have while giving the rehabilitative therapy.
-what is your feeling on such attitude?
-what do you think of the relationship with the medical practitioners?
-the meaning of this kind of relationship to you.
-do you like it? If not, what kind of relationship does you expect?

-your appraisal of the rehabilitative therapy received.

7. The social services received in the past and now.

-what are the services?

-the effect/ need of the services you mentioned above.

-what are the reasons?

-the attitude you believe the professionals/ staffs should have while giving the rehabilitative therapy.

-what is your feeling on such attitude?

-what do you think of the relationship with the professionals/ staffs?

-the meaning of this kind of relationship to you.

-do you like it? If not, what kind of relationship does you expect?

-your appraisal of the rehabilitative therapy received.

8. Caring and establishing of healthy life.

-the general healthiness of the impaired who have to use wheelchair.

-is there any obvious division of different degree of healthiness?

-if yes, what is the conception of such division?

-who would be responsible for such division?

-do you concern about the usage of specific caring method or establishing a kind of healthy life.

-why?

-what would be necessary to you if using specific caring method or establishing a kind of health life?

-what kinds of methods/ formats would you use?

-why?

-how do you know about such methods/formats?

-the assistance/effect on your health after using those methods.

-what do you think of the role and the division of labour of the disabled, professionals and government on health maintenance?

-what do you think of the responsibilities of the disabled, professionals and government on health maintenance?

-why?

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