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**THE SOCIAL CONSTRUCTION OF  
DISABLING IDENTITIES:  
SEVERELY VISUALLY IMPAIRED CHILDREN  
IN LEBANON**

**Maha Ghazi Damaj**

London School of Hygiene & Tropical Medicine

PhD thesis

2008



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## **ABSTRACT**

*'The Social Construction of Disabling Identities: Severely Visually Impaired Children in Lebanon'*

The purpose of this study is to investigate the current Lebanese social policy and practices concerning disabled children in general and visually impaired children in particular on the social construction of disabling identities. This is relevant to current national and global disability rights movements, which infrequently take children and their specific issues into consideration. It is particularly pertinent to Lebanon which passed its first rights-based disability law in 2000 and continues to struggle with its implementation.

This study was conducted through an organisational ethnography of a residential institution for children with severe visual impairments and was supplemented by interviews with the children, some members of their families, teachers, staff and alumni from the institution, as well as participant observation sessions at integrative settings, and interviews with parents and activists pursuing inclusion. The analysis focused on investigating the inclusionary versus exclusionary nature of policy and practice; the availability of mechanisms allowing for children's participation in these contexts; and the impact of these practices on the self-identities of disabled children. Theoretically, the analysis built on current literature in disability studies and the sociology of childhood, as well as drawing on Foucauldian ideas of power, control and surveillance and applying Goffman's concepts of stigma and the concept of a total institution. The findings show that rights based legislation cannot on its own result in inclusive changes of policy and practice. In the absence of implementation mechanisms, practices remain predominantly exclusionary, with no effective mechanisms for the meaningful participation of parents or children, eventually socialising the children into disabled identities. Children 8 - 12 years of age were not exhibiting any noticeable resistance to the systems of control, and had adopted the discriminatory values relating to disability exhibited around them.

*This thesis is dedicated to my family*  
*- Ratiba, Ghazi, Ossama and Faissal -*  
*for their enthusiasm and unwavering support,*  
*and for constantly pushing me to challenge my own limitations.*

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# TABLE OF CONTENTS

GLOSSARY .....	7
ABBREVIATIONS .....	8
APPENDICES .....	9
TABLES & FIGURES .....	9
INTRODUCTION .....	10
CHAPTER 1 – LITERATURE REVIEW ON DISABILITY & DISABLED PEOPLE .....	13
A. Introduction .....	13
B. Representations & Constructions of Disability .....	14
C. Models of Disability Theory .....	31
D. Rights, Needs & Oppression .....	43
E. Approaches to Working with Disabled Persons .....	55
F. Conclusion .....	61
CHAPTER 2 – LITERATURE REVIEW ON CHILDREN & CHILDHOOD .....	64
A. Introduction .....	64
B. Children within their Social, Cultural & Political Contexts .....	65
C. Power & Control .....	81
D. Conclusion .....	84
CHAPTER 3 – RESEARCH METHODS .....	87
A. Rationale & Aims of the Research .....	87
B. Research Methodology .....	87
C. Research Setting .....	92
D. Study Population .....	94
E. Research Methods .....	96
F. Data Analysis & Emerging Themes .....	105
G. Conclusion .....	106
CHAPTER 4 – LEBANESE POLICY CONTEXT • PAST & PRESENT .....	107
Introduction .....	107
Part I – Background .....	108
Part II: Review of Social Policy in Lebanon Concerning Disabled Persons .....	120
CHAPTER 5 – PROCESSES OF EXCLUSION & INCLUSION IN THE INSTITUTION .....	142
Introduction .....	142
Part I – Space & Time .....	145
Part II – Mechanisms, Structures and Strategies of Authority & Power among Staff and Students .....	161
CHAPTER 6 – OUT OF PLACE • FAMILY RELATIONS & BELONGING .....	207
Introduction .....	207
A. Home Environment & Belonging at BAL .....	210
B. Creating Links between BAL & Families .....	220
C. Community Links .....	224
D. Parents' Roles & Family Relations .....	228
E. Perceptions of the Child, Representations of the Disability .....	240
F. Conclusions .....	242
CHAPTER 7 – SELF & OTHERS • DISABLING IDENTITIES .....	245
Introduction .....	245
A. Normality & Normalisation .....	246
B. Self Perceptions, Aspirations & Role Models .....	259
C. Belonging to a Group / Identifying with the Disability .....	266
D. Conclusions .....	270
CHAPTER 8 – CONCLUSIONS .....	274
A. Methodological Issues – Strengths and Limitations .....	275
B. Main Empirical Findings .....	278
C. Main Theoretical and Empirical Contributions to Knowledge .....	286
APPENDIX 1 – INTERVIEW TOPIC GUIDES .....	291
BIBLIOGRAPHY .....	293

## GLOSSARY

ì`aāqa	.....	Disability
mu`aāq	.....	Disabled
mu`awwaq	.....	Disabled person
dhawiyy hājāt khāssa	.....	Persons with special needs
jam`eyyat tathalluth as-sabaghiya 21	.....	Association for trisomy 21 (LDSA parents' association)
dhawiyy qudurāt mukhtalefa	.....	Persons with different abilities
dhawiyy ehtiyājāt edāfiyya	.....	Persons with additional needs
majdhoob ila Allāh / majdhoob / majdoob	.....	Attracted to God / colloquial versions
Walīd	.....	Newborn
radī	.....	Infant that is being breastfed
Fatīm	.....	Infant no longer being breastfed
Sabi	.....	Boy
Bint	.....	Girl
fata / fatat	.....	Young boy / girl coming of age
nāshe'	.....	Child who is growing up, reference to fruits of child-rearing appearing
yāfe`	.....	Young person
Murāheq	.....	Adolescent
shāb / shāba	.....	Young man / woman
Rajul	.....	Man
imra'a	.....	Woman
kahl / kahla	.....	Middle aged man / woman
`ajooz	.....	Elderly person – connotation of incapacity
Zakāt	.....	Charity tax introduced in Muslim practice
Sadaqa	.....	Charity
dawhu / `eshsh	.....	Nest
bayt / dār	.....	House, home, family
`eid	.....	Holiday celebration
a`ama	.....	Blind

*The Arabic to English transliteration system adopted in this thesis is that of the International Journal of Middle East Studies (IJMES 2007)*

# ABBREVIATIONS

ARC	Arab Resource Collective
CRC	Convention on the Rights of the Child
LDSA	Lebanese Down Syndrome Association
MoSA	Ministry of Social Affairs
NCDP	National Council for Disabled People
NGO	Non-governmental organisation
NIP	National Inclusion Project
UNESCO	United Nations Educational, Scientific & Cultural Organisation
UNRWA	United Nations Relief and Works Agency for Palestinian Refugees in the Near East
WHO	World Health Organisation
YAB	Youth Association of the Blind

## **APPENDICES**

Appendix 1: Interview Topic Guides .....	292
--	-----

## **TABLES & FIGURES**

Table 1.1: The Child and the Environment in three different contexts .....	55
--	----

Table 3.1: Chart of Data Collected .....	97
--	----

Box 1: Redefining 'ability' .....	53
-----------------------------------	----

Diagram 1.1: The main parameters of integration and inclusion in a school setting .....	59
---	----

Figure 4.1: Map of Lebanon.....	108
---------------------------------	-----

Box 4.1: An example of the representations of ages and roles in the Arabic language ....	114
--	-----

Figure 5.1: Map of School (Ground Level).....	149
---	-----

Figure 5.2: Map of School (First Floor) .....	150
---	-----

Figure 5.3: Organisational Chart at BAL.....	162
--	-----

# INTRODUCTION

This thesis sets out to explore the social constructions of the social identities of disabled children through a case study of the practical understandings and interpretations of inclusion as reflected in contemporary policies and practices in Lebanon in relation to severely visually impaired children. Specifically, this is a qualitative case study of the lives of severely visually impaired elementary school children attending a specialised residential institution, and it is an analysis of the social construction of the identities of visually impaired children attending a segregated institution, in relation to their local communities and the wider society.

The theoretical framework of this thesis is drawn from literature in the areas of sociology of childhood, and disability studies, as well as Foucauldian and rights based concepts. The development of studies in the sociology of childhood over the last two decades have introduced child-centred concepts in health, education, social work and various other fields. Children have been studied as active subjects in their different environments (home, school, social services). Proponents of the social model of disability argue that discriminatory perceptions of disability and disabled persons, and the ensuing structures that are put in place, both physical and organisational, create disablement. Theories of inclusion expanded this notion by addressing discriminatory attitudes and practices, advocating a respect for diversity and individuals, and demanding equal opportunities for everyone to participate in decision-making in their daily lives through exercising rights and having choices. The social model of disability has been subject to a number of critiques calling for more consideration of impairment, gender, ethnicity, social attitudes and multiple identities, but remains valid in its primary assertions of causes of disablement, and it is these concepts coupled with these considerations that are adopted here. This thesis reflects a rights-based approach both to work with children and with disabled people, and adopts a

Foucauldian approach to issues of power, surveillance, control and resistance in relation to the lives of disabled children.

This thesis sets out to investigate the following research questions:

1. To what extent do current policies and practices in Lebanon foster inclusion versus exclusion of disabled children under 12 as part of a rights based approach?
2. What are the mechanisms and processes that allow the voices of severely visually impaired children in residential institutions to be heard?
3. How do elements of inclusive and exclusive practices impact on the social identities of severely visually impaired children in Lebanon?

These research questions will be addressed through a Lebanese case study with an analysis of current policies and their implementation, by eliciting the voices of severely visually impaired children and analysing their views on their lives in their households, schools and communities, and by similarly eliciting the views of their families and professional carers of their perceptions of the visually impaired child's capacities. The study utilises qualitative research methods including participant observation and interviews, which are deployed in an organizational ethnography of one institution that forms the principal case study. In addition, some limited observation and interviews were carried out in two other contrasting educational settings. It thus looks into the gap between legislative and policy rhetoric, rooted in a rights-based approach, and the current service provision and practice for visually impaired children in Lebanon.

The three research questions are addressed in the findings chapters; Question 1 is addressed in Chapters 4 and 5, Question 2 in Chapter 5 and Question 3 is addressed in Chapters 6 and 7.

I chose this topic for my PhD dissertation owing to my commitment to working with disabled children. I have been working with child rights organisations for some years on programmes and initiatives aimed at furthering children's participation and promoting the work of the advocacy lobby in Lebanon for developing more inclusive systems and practices for disabled children, through community practice and through activating the comprehensive implementation of Law 220.

This thesis makes an original contribution to empirical and theoretical knowledge in relation to children with disabilities in the areas of social policy, disability studies, and the sociology of childhood through this Lebanese case study.

# CHAPTER 1 – LITERATURE REVIEW ON DISABILITY & DISABLED PEOPLE

## A. Introduction

*'Writing about the memorial service for disabled civil rights activist Timothy Cook, Joseph Shapiro concluded that 'Nondisabled Americans do not understand disabled ones'. His conclusion was derived from the heartfelt tributes of Cook's non-disabled friends. "He never seemed disabled to me" said one, "He was the least disabled person I ever met", pronounced another.' Shapiro's analysis of this discourse is worth repeating.*

*"It was the highest praise these nondisabled friends could think to give a disabled attorney who, at thirty-eight years old, had won landmark disability cases, including one to force public transit systems to equip their buses with wheelchair lifts. But more than a few heads in the crowded chapel bowed with uneasy embarrassment at the supposed compliment. It was as if someone had tried to compliment a black man by saying, 'You're the least black person I ever met', as false as telling a Jew, 'I never think of you as Jewish', as clumsy as seeking to flatter a woman with, 'You don't act like a woman'.*

*Here in this memorial chapel was a small clash between the reality of disabled people and the understanding of their lives by others. It was the type of collision that disabled people experience daily. Yet any discordancy went unnoticed even to the well-meaning friends of a disability rights fighter like Cook ... taking pride in his disability was for Cook a celebration of the differences among people and gave him a respectful understanding that all share the same basic desires to be full participants in society.'*

(Shapiro 1994 quoted in (Slee 1999):122)

This chapter reviews literature in the field of disability studies, engaging with models of disability and different approaches, and explores the underlying representations and social constructions of disability and disabled persons. The influence of history, language, culture, medicine, economics or policy on our perceptions and norms concerning disability are discussed.

The literature on models of disability deals with primarily the medical and the social models of disability. Each of these models has a specific focus that results in a social construction of disability that either places the burden of the impairment on the disabled person, or on the social environment. These are reflected in the use of language and labelling, economic discrimination, and in the stigma and stereotypes attached to disability. Issues pertaining to discrimination,

oppression and rights emerge from within these constructions and the resulting social policies and practices.

Furthermore, dissecting these elements of the social constructions of disability sheds light on the efficacy of policies, interventions and programmes directed at disabled persons – in rehabilitation, education or re-integration. As the main focus of this study is children, the settings and programmes that children are placed in to respond to these policies are also described, along with other interventions that aim at inclusive values.

Throughout this thesis, reference to the group of people who have an impairment that has disabled them shall be made by calling them “disabled people / individual / person”. This is intended to identify ‘disabled people’ as a separate social group. The argument that supports the use of this terminology as opposed to the other equally used ones – such as ‘the disabled’, ‘people with disabilities’, etc. – is highlighted in the section on language and labelling.

## **B. Representations & Constructions of Disability**

### **I. History and Economics: the evolution of the disabled social group**

Disability and impairment are not new and have made appearances in texts dating as far back as Ancient Egypt. The Egyptians were the first to associate the brain as the centre of control for the lower limbs and for speech, which may have provided grounds for associating such disabilities with ‘abnormal’ mental functioning. Plato’s *Republic* recommended putting away deformed offsprings ‘in some mysterious, unknown place, as they should be’ (Safford and Safford 1996:4). Aristotle made the connection that deaf people would inadvertently be mute, and his unfortunate choice of words to describe this; *kophi* (deaf) and *eneos* (speechless); became associated in the

language with connotations of 'stupidity', and that these people lacked the natural existence of language, such that it was 'pointless to teach them' (Safford and Safford 1996:7).

Disabled people were either seen as deviant, or an outcome of the parents being cursed, or as an indication of infidelity. A sometimes illegal, but socially acceptable practice was to abandon them or leave them to die. While disabled people were granted dignity in some societies, 'a shift in Western culture from extermination to *ridicule* came with the beginning of the Christian era, when Romans could purchase a human being with physical deformities for amusement' (Safford and Safford 1996:3). Children with disabilities were sold or picked up by those who would use them in side shows, or send them out to beg. Their disabilities were sometimes accentuated or induced to make them more effective beggars or attractions.

Such practices were not exclusive to specific cultures and were seen in literary or other images in the Arab world as well. The standpoint towards disability, however, was influenced by the prevailing Islamic faith which ascribes everything to the will of God. As such, 'society tends to perceive disability as an act of God testing the faith of individuals to determine who is able to accept and tolerate their fate with gratitude and patience and those who are not' (Turmusani 2003): 52).

Disability is often linked with poverty, and it would seem that impoverished conditions can sometimes lead to impairment in children, and does not provide the means with which to prevent them.

Some writers posit that in pre-industrial times, economic activity was agrarian, and included the labour contribution of disabled people. They accordingly participated socially and economically, albeit from the lower rungs of the social hierarchy which also held the poor and unemployed.

Finkelstein (cited in Barnes 1999) refers to this as Phase One in the three distinct, sequential historical stages of disabled people.

Phase Two came about with the onset of the industrial revolution in the nineteenth century. The introduction of manufacturing technology required a 'pair of hands', average workers, and anyone who did not fit into this category quickly became unemployed. The emergence of increasingly sophisticated machinery also meant that potential workers had to be able to follow instructions, which were often only provided in oral or written form. The widespread dominance of such technology augmented the importance of 'normality' 'as well as the importance of designing machinery, buildings and transport systems to places of employment for normal people' (Finkelstein 1993:12). Stressing 'normality' also encouraged the suppression of non-normal behaviour 'such as the use of signing for communication, or the exclusion of those who could not see or walk' (Finkelstein 1993:12).

This phase was characterised by the separation of disabled people from the rest of society (Oliver 1990). Furthermore, it has been argued that the exclusion of the disabled individuals 'from the mainstream of economic and social activity was the justification for segregating individuals with impairments in a variety of residential institutions, defining them as in need of care and supervision' (Barnes 1999:83). This era witnessed the gradual crystallisation of the individual model of disability theory, and the emergence of the medical and administrative model that was dominant for many years in the field of disability (See Section C in this chapter). These 'personal tragedy' models perceived the impairment as a misfortune, a source of incapacity, and focused on rehabilitating the disabled person in order to regain 'normal' function. Consequently, these models underpinned the scientific justification for the limited social and economic roles and responsibilities of disabled people. Disabled people were perceived as having special needs, were excluded from economic activity, and special programmes and institutions were designed to cater to their needs. Raising funds for these services and for the development of more advanced technological aids to

assist disabled individuals in leading 'normal' lives, relied heavily on charity, and on an image of disabled people as pitiful and in need of help (Barnes, Mercer et al. 1999).

The third phase in Finkelstein's material historical account of disability is taking shape currently in societies that are characterised as being 'highly developed' (Oliver 1990:29) and 'corresponds with the emergence of post-industrial society, and sees developing technology as the harbinger of social and economic revolution' (Barnes 1999:83). That is, it considers technology and the development of appropriate devices as the path towards the reintegration of disabled people in society (Oliver 1990). This technology 'will facilitate the liberation of disabled people as people with impairments work with others in society to achieve common goals based on general human needs' (Barnes 1999:83). Examples of such technology are software and hardware accessories that allow people with visual impairments to operate computers – and thus any equipment that connects to computer technology – through audio or Braille translation, automatically adjustable work-benches and car adjustments for people with physical disabilities, and so on. As such, it can be said to mirror the principles of the social model of disability theory that seeks to remove disabling barriers, and of current movements in the field of disability.

### ***The Role of Economics***

Economics has historically played either a direct or indirect role in shaping perceptions of people with disabilities. Finkelstein refers to the importance of 'social wealth' (Finkelstein 1993):12), and that the inability of certain groups to contribute to this was a disabling and marginalising factor.

Economics was a key factor in the development and maintenance of the social and welfare services that were made available to people with disabilities. This was both in terms of the tragic images of disabled people that are employed to run charities and gain funds, and in terms of being

funded from public coffers which took issues related to disabled people out of the personal domain and into the public one.

The possible onset of impairment may be affected by the socioeconomic status of the household. Poverty and low socio-economic status and difficult living conditions are frequently linked to insufficient or poor pre- and post-natal care, which is repeatedly cited as a cause of impairments in children. Another aspect of economics and its impact on the family of a disabled person is the direct and indirect costs of care. Direct costs being the costs of accessing and paying for care, and indirect costs being household costs related to the disability. For example, the 'direct consequence of having a disabled child is that the mother's participation in the paid labour market is severely constrained' (Barnes 1999:99), further compounding a family's economic difficulties. Additionally, this restricts opportunities to afford appropriate education for disabled children, and 'low levels of education deny people the opportunity to gain knowledge and skills necessary to integrate in the formal labour market, where pay, benefits and working conditions are typically more advantageous than the informal economic sector.' (Wehbi 2006): 332)

These economic factors contribute directly or indirectly to marginalising and disabling people with disabilities, as well as hindering them from overcoming these economic difficulties through their own efforts. Hence, both through the operation of the labour market and by the social organisation of work, the economy can be found to play 'a key role in determining societal responses ... to disability' (Oliver 1996:132).

Thus over the years, society can be seen as affecting, and being affected by, different ways of theorising and conceptualising disability. This cultural production of disability was not only moulded by beliefs, practices and overriding social currents of the times. It has also been found to be heavily affected by economic factors, such as 'the type of economy, the size of the economic surplus and the values that influence the redistribution of this surplus' (Oliver 1990:24).

## II. Language and Labelling

Language, as a form of communication, describes and defines the world around us in common terms and concepts that we may all understand and share. The nouns and labels that are produced carry social meanings and are rarely neutral. They form the identity of the subject being described. Therefore, focusing on language draws a picture of the social perception of the subject, and depicts his/her position in the social structure and distribution of power.

'... it (language) is about deeply held values concerning the social position of people with disability where disability is perceived as a personal deficit and a moral failing.' (Hogan 1999:79)

While searching for the disabled person in an average descriptive conversation or passage, it is of note that 'non-disabled is presumed unless otherwise stated' (Swain and Cameron 1999:68). Similar to the assumption that the subject is heterosexual or white, unless otherwise stated. That disability, or homosexuality, require these adjectives while their counterparts do not, not only stresses this difference, but also projects it as abnormal.

The most commonly used adjectives to describe a person who is not able-bodied are 'handicapped', 'impaired' and 'disabled'. The Oxford dictionary (Oxford 1997) definitions of these terms as they exist outside the disability literature are as follows:

- **impaired** (*adj.*) / **impair**: *v.* damage, weaken. **impairment** *n.* (1997:257)
- **disabled**: *adj.* having a physical disability. **disablement** *n.*  
**disability**: *n.* something that disables someone; a physical incapacity.  
**disable**: *v.* deprive of some ability, make unfit. (1997:143)

- **handicap**: *n.* a disadvantage imposed on a superior competitor to equalize chances; a race etc. in which handicaps are imposed; something that makes progress difficult; a physical or mental disability. • *v.* (**handicapped**) impose or be a handicap on. (1997:235)

The usage of these terms in our daily communication, when not in a disability context, carries meanings of imperfection, weakness, impotence and uselessness. Even if it was claimed that they were not the images that are conjured up in our minds as we use these terms when speaking of disability, they inevitably affect the self-image of the disabled person him/herself. The word "handicap" originates as an abbreviation for "hand-in-cap", referring to the large number of disabled individuals who were beggars throughout history.

The WHO explanatory document (WHO 1980) bestowed a scientific nature upon these terms when it adopted them to differentiate states of disability, and defined them as follows:

- Impairment: 'Any loss or abnormality of psychological, physiological or anatomical structure or function' (1980:27)
- Disability: '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' (1980:28)
- Handicap: 'A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex, social and cultural factors) for that individual' (1980:29)

The critiques of these WHO definitions have focused on their largely medical categorisations, and on the recurrent notion of 'normality' and the able-bodied assumption that everyone should strive to be 'normal' like them (Barnes 1999).

In terms of cross-cultural usage, the literal translation of these terms into different languages have frequently produced terms that are more heavily stigmatised than the original English one. In the Arabic language, “*ʾaāq*” is used to refer to a disability, and words from this root are equally used to refer to certain constraints, such as those of time, responsibility, etc. But the word stands on its own to clearly mean disability. A disabled person was referred to as “*mu`aāq*”, reflecting that he/she carries a disability that prevents them from functioning normally. Not unlike words such as “spastic”, “cretin” or “retard” that filtered into conversations amongst non-disabled persons as a form of insult, “*mu`aāq*” has played a similar role in the colloquial Arabic language. In recent years, possibly as an outcome of the WHO categories, the word “*mu`awwaq*” (‘disabled’) has been adopted, with the “*ww*” accent implying that the cause of the disability is in the surrounding environment and not the person him/herself. In the Arabic milieu, the dialogue over the language of disability continues. The equivalent of ‘people with special needs’ (“*dhawiyi hājāt khāssah*”) encompasses all special needs, including children/ people in difficult circumstances., but is also loosely used as a politically correct description for disabled people.

In a regional workshop on Early Childhood Education and Inclusion (ARC, July 1998), a founding member of the Lebanese Down Syndrome Association (LDSA), an organisation formed by the parents of children with Down Syndrome, requested that the workshop adopt the phrase “children with disabilities” as opposed to disabled children, in order to emphasise that the subject is first and foremost the child/children. The LDSA’s Arabic name also hinges on the social meanings attached to the most commonly used word for Down syndrome, “mongoloid” or “*mongoli*” and has chosen to name itself “*jam`eyyat tathalluth as-sabaghiya raqem 21*” (Society for children with Trisomy 21) in reference to the trisomy of chromosome 21, which is the cause of Down syndrome. In this instance, using scientific medical terms is not intended to fall into the medicalisation of the disability, as much as shifting the focus away from the socially unfavourable stereotype of a “mongoloid” child.

Indeed, with these terms and with other labels that were used to describe disabled people, images emerge that describe them in terms of what they could not do, while the identities of their non-disabled peers were being defined in terms of what they could do (Swain 1999). Along this line of reasoning, another term appeared. At a more recent meeting of the same group of organisations mentioned previously (ARC, June 2000), an Egyptian organisation that has spawned countless community-based rehabilitation and portage programmes for disabled children, their siblings and parents (SETI-Caritas), proposed yet another term for 'persons with special needs', calling them instead 'persons with different abilities' (*"dhawiyy qudurāt mukhtalefa"*), and even coined 'dif-ability' as a substitute for 'disability'. In Lebanon, an Inclusion Network that was established in 2002 consisting of disabled people's organisations and parents' organisations coined another term that is gaining popularity in the region – children with additional needs (*"dhawiyy ehtiyājāt edāfiyya"*). The Inclusion Network explains this phrase as follows:

***WHY WE USE THE EXPRESSION «ADDITIONAL NEEDS»?***

***The child's basic needs are vital for the insurance of the natural growth of every child across the globe.***

***Children's needs are the elements, the circumstances, the regular or variable means necessary, whether instantly or permanently, for every child to fulfil himself/herself and to achieve his/her full potential.***

***Children with additional needs share the same feelings and desires as all other children. However, they also have different additional needs in comparison with other children***

Inclusion Network, 2002

Juliet was right in saying that "A rose by any other name smells just as sweet...", and whether one chooses one label or the next, the only truth that remains is the impairment itself. Finkelstein would add that 'replacing one label with another while the day-to-day reality of disability remains unchanged seems to be an exercise in changing fashions, even adding more confusion to the relationship between impairment and disability' (Finkelstein 1993: 11). But the labels were never intended to hide the disability. They reflect how societies perceive disability, and disabled people.

As Priestley noted, 'the way we acquire and use language not only reflects our relationship to the wider social world, it also reproduces it' (Priestley 1999:92).

When describing the impact of a modern slogan describing people with disabilities in the Chinese language, Emma Stone echoed the common fear 'that new discourses imposed or imported may give an impression of newness, neutrality and positive change without fundamentally challenging or dismantling the cultural and material structures constituting disability in China' (Stone 1999:146). Yet her study also showed that this was not the case and that society slowly began to change after the adoption of the new slogan "Canji erbu canfei" that transforms the disabled individuals from "useless" (canfei), as was the commonly held, to "disabled" (canji); and thus they were "disabled but not useless" (Stone 1999:136).

Additionally, language plays a discriminatory role in the jargon that is used by medical or technical professionals dealing with disability and disabled people. At the medical level, the disability is the impairment, and its treatment, and the disabled person's response to it are scientifically categorised into cause and effect groupings that not only belie the disabled person's individuality and disability, but it may also remove him/her from the formula altogether. The decision-making process may also employ technical jargon that can render the information inaccessible to the disabled person concerned, thus obstructing their choice and control over their own situation (Morris 2004).

At the policy and rights level, the legal terminology employed to ensure or protect the disabled person's rights may exclude him/her from the discourse. The specialised terminology and language 'reinforces the power and authority of the professionals who use it: politicians, local authority officials, lawyers and educational psychologists, for example'. (Aspis 1999:175)

It can, therefore, be seen how language and labelling reflects the prevalent social perceptions of disabled people and can be used to exclude disabled people themselves. This also reflects the formation of the disabled identity, both socially and individually, as will be illustrated in the following section.

### **III. Disabled Identities: social representations, stereotypes and stigma**

*'The social world differs from the natural world in (at least) one fundamental respect; that is, human beings give meanings to objects in the social world and subsequently orientate their behaviour towards these objects in terms of the meanings given to them.'* (Oliver 1990:2)

Social identities are constructed and maintained by widespread norms and images. It is thus that the social identity of a doctor is considered to be dignified, almost omniscient and powerful; that that of a teacher is regarded as well-learned and respectable, and so on. Moreover, these people are expected to remain within this social identity and behave in a correspondingly suitable manner. Yet these individuals do not necessarily carry these traits intrinsically, and this social construction of their identity differs between communities where the role they play may also be different. For example, scientifically trained doctors may not be held in the same respect in communities that have long relied on traditional healers, and teachers who introduce concepts that interfere with traditional practices are considered a nuisance and a threat. (Lemert and Branaman 1997)

Disabled people, as a social group, are similarly subjected to such a socially constructed identity. It has been argued that it is socially constructed precisely due to the fact that the understanding and projection of disability differs from one society or culture to the next. 'Indeed, in some cultures

and languages, there is no term for 'disability', and social 'difference' is categorized in many different ways' (Barnes 1999:14).

### ***Representing disability***

The social representation of the disabled individual can be found in literature, film, art, language and all other forms of communication. These are influenced by cultural beliefs and social attitudes, which both affect and are affected by widespread practice, policies and the division of labour.

Swain argues that 'within literature and other forms of cultural representation, discourses of disability and disabled people tend to be one-dimensional, dealing with stereotypes' (Swain 1999:71). Barnes (cited in Swain 1999) observes that 'the disabled person is either (a) a sad, pathetic victim; (b) a tragic but brave hero; (c) an evil, twisted villain.' (Swain 1999:71)

Mentally ill people are also traditionally portrayed as being 'simple but closer to God' (Shakespeare 1999:167). This also exists in the Arab culture where the name "*majdhoob*", which colloquially became "*majdoob*", meaning 'simple-minded', originates from "*majdhoob ila Allāh*" or 'attracted to God'. In Shakespeare's description of the portrayal of people with mental disabilities or illnesses in film, he goes on to say that they are often 'infantilised' (Shakespeare 1999:168) and that the representations themselves become disabling.

Barnes, Mercer and Shakespeare (Barnes 1999:194) list five general classifications of the cultural representations of disabled people as follows:

1. Medical: disability as illness or malfunction;
2. Social pathology: disabled people as disadvantaged, needing support;

3. 'Supercrip': disabled people as deviants, achieving super-human feats in spite of impairment;
4. Civil rights: disabled people having legitimate grievances, as members of a minority group;
5. Cultural pluralism: disabled people as multi-faceted, impairment not the only issue.

They extended these to include:

6. Business: disabled people as costly to society, particularly commerce;
7. Legal: disabled people possessing legal rights;
8. Consumer: disabled people as an untapped market.

The individual medicalised model of disability views the impairment as needing treatment and places the burden of adjusting the effect of the impairment upon the disabled person. The 'tragic victim' will never be completely 'normal' and will thus be incapable of supporting him/herself, and will need to be cared for, financially and medically, by the productive members of society (representations 1, 2 and 6 above). The sociologist Robert Bogdan argues that the medicalisation of disability resulted in the 'growth of organized charities, the rise of professional fund-raising, and the invention of the poster child, with pity used as the dominant mode of presenting human difference' (Bogdan 1988).

These models have also contributed to the 'supercrip' image and the stereotypical 'villain'. The former image is created since the disabled person is considered too impaired to be able to perform any worthy feat and is thus 'superhuman' when he/she does; and in the latter it comes about since this tragic disability will undoubtedly leave the person bitter and vengeful. Additionally, the 'supercrip' is lauded for managing to achieve 'normal' feats despite his/her disability, and the 'villain' typifies the social deviance that will ensue if the disabled person does not learn to deal well with the 'tragedy'. This perceived deviance also appears in some accounts as an additional

reason supporting the institutionalisation of the disabled individuals and segregating them from the rest of society.

All of these images emphasise the 'spoiled' identity of the disabled individual and their differences from the rest of society. 'Interpretations of 'able-bodied' normality in terms of body shape and capacities become intertwined with moral and social virtues' (Barnes 1999:64). The practice of institutionalisation and medicalisation inspired by the individual medical model of disability still heavily contributes to the emphasis on the 'abnormal'.

Deborah Stone (Stone 1985) also argues that disability is socially constructed in that it is defined by policy-makers. Her argument assumes that societies are founded on distributive systems based on work or need, and thus the lines defining 'disability' are affected by the standards of labour expected from, and provision for, these individuals. The roles of welfare and service provision as brought about by the individual model are outlined in some detail in the following section, as is the equally powerful administrative model of disability. These were propagated by the image of the 'tragic', 'helpless' and 'pitiful' disabled person, and are not necessarily representative of the disabled person's rehabilitative needs. This constructed disabled person was, equally, the person who should not be burdened with social responsibilities and decisions, and so these were taken care of for him/her. A person with such traits and limited capacities compared poorly to the image of the productive worker for whom most jobs are generally designed, and thus the disabled person's place in the work force disappeared as well, as discussed in Section I. Yet, no doubt the distributive system of work that Stone refers to would equally create facilities for disabled people to work in if the general economy required their contribution to the workforce, regardless of their disability. Thus she asserted that people are socialized into the 'disabled' role; and that the 'categorization is legitimated by the medical and welfare bureaucracies' (Barnes 1999:70).

Writers on the body and society such as Scheper-Hughes and Lock (1987) identify:

'the individual body, understood in the phenomenological sense of the lived experience of the body-self... the social body, referring to the representational uses of the body as a natural symbol with which to think about nature, society, and culture... (and) the body politic, referring to the regulation, surveillance, and control of bodies (individual and collective) in reproduction and sexuality, in work and in leisure, in sickness and other forms of deviance and human difference' (Scheper-Hughes and Lock 1987: 7-8), 'where the concern is with the social regulation of the individual and collective bodies to promote social stability' (Barnes 1999:63).

The 'societal bio-politics' of the body and the control of the disabled person has been illustrated in the context of policies, economics and welfare services that have generally segregated him/her from society. The role of the social body and the symbolism in language and labelling of disabled individuals was explored in the previous section on language and labelling, and the symbolic images of the disabled person are mentioned above. The focus on the 'individual body' has the power to place that experience in a positive or negative light. These different dimensions of the disabled identity and the social construction of disability are often linked to stigma.

### ***Disability as stigma***

Goffman, in his landmark study of Stigma (1963) stated that 'the Greeks ... originated the term stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier' (Goffman 1963:11). This is usually followed by a marginalising process that maintains the stigmatized person outside the mainstream, and brands him/her with a sense of shame, guilt or anxiety for lacking something, or possessing something that is considered undesirable (Hogan 1999: 83).

These stigmatizing attributes are set by society and define a comparative relationship between persons who are stigmatized and those who are not. Thus 'an attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself' (Goffman 1963:13). Moreover, 'the social identities of those who consider themselves to be normal (or non-disabled or able-bodied) are secured only through a process which involves the systematic social exclusion and marginalization of others ('the disabled'), who are identified in terms of their deviance from an imagined ideal' (Swain 1999:75).

These are the situations under which disability becomes a stigma, and where the disabled person becomes socialised into a stigmatized, spoiled identity. As a result, disabled people also fall into the role of managing their stigma in a manner that will allow them to be more readily accepted in society. Goffman refers to three strategies in managing disability: 'passing' for normal and non-stigmatized; 'covering' the stigma so that it does not overwhelm social encounters; and 'withdrawal' from social activities with 'normals' altogether (Barnes 1999). The visibility of the stigma is directly related to the ease of dealing with it such that a stigma (or disability) that is not visible, and that allows the disabled person to 'pass' for 'normal', offers him/her a 'limited form of liberation – that one had overcome one's disability' (Hogan 1999:83).

These stigmas are compounded by the surrounding physical and social worlds that react to emphasize the stigma further. 'We receive so many messages from the non-disabled world that we are not wanted, that we are considered less than human. For those with restricted mobility or sensory impairments, the very physical environment tells us we don't belong. It tells us that we aren't wanted in the places that non-disabled people spend their lives – their homes, their schools and colleges, their workplaces, their leisure venues...' (Morris 1993:104)

Society is uneasy in dealing with stigma/disability (Barnes 1999), and goes through its own phases of ignoring stigma or 'normalizing' it. 'Normalization' has most clearly appeared through persons

who are related or are close to the stigmatized person, and who through this relationship acquire a 'courtesy' stigma (Goffman 1963). This process allows them to show how far 'normals' can go in treating the stigmatized person as if he/she did not have a stigma. The stigmatized person may also attempt to 'fit in' and re-integrate into society by appearing as 'normal' and non-disabled as possible, which are the terms under which society will take them back in.

The effects of such stigma are well expressed when wondering 'Why is it that some disabled people confront the barriers they face, while others prefer to 'get by'?' (Finkelstein and French 1993:32). How far have they been socialised into a stigmatized and dependent role? Setting aside individual differences, this question is raised in an exploration that aims to arrive at a psychology of disability. It becomes gradually clear that the main psychological issue regarding disability is not strictly related to the loss of a limb or function, as the psychology of the individual model has emphasized, but to the social stigma that accompanies disability.

The insistent trait that these common representations of disabled people portray are of a person who is, for all accepted purposes, 'socially dead' (Abberley 1993); (Finkelstein 1993). Yet this 'socially dead' and 'incapacitated' role that challenges the disabled person's ability to care for him/herself, or make his/her own decisions, or raise children, or live independently among the rest of society, etc. has been questioned in settings where the general practice of the community was diametrically opposed. Groce (Groce 1985) described a community in Martha's Vineyard in Massachusetts which contained a high proportion of people born with congenital deafness. It was noted that, in response to this, the larger part of the population, both deaf and hearing, became bilingual in a sign language. There were consequently none of the communication barriers that deaf individuals ordinarily face, and they thus played equally active political, professional and social roles as everyone else in their community. Another community in northern Ghana was afflicted with River Blindness that left almost 40% of its population blind. An agricultural rehabilitation project for the blind in this village was covered by BBC (*In Touch*, November 9,

1999). The programme illustrated how blind men and women were able to tend their own land, contribute to the collective produce of the cooperative, and go about their daily work and life with little trouble. This was a process that gradually came about through grass roots community work which developed ways to involve the blind members in the community's cycles of production. In the process, these blind persons attained a level of acceptance in their communities that was uncommon for blind individuals in general.

In these small-scale societies, the identity of the person was far less linked to his/her individual impairment. That is, the 'spoiled' identity becomes less as the impairment is separated from the disability (Corker 1999), and from the person, and it is communities such as those of Martha's Vineyard and northern Ghana that prove this point. It could be said that such a distinction retains individuality outside of any group identity, and as such 'lacking a collective identity, people with disabilities are not set apart, their bodily difference being seen instead as a mark of their individual personhood' (James and Hockey 2007): 79). The disabled person may choose to force this change by 'coming out' as disabled, and by redefining their personal identity, they redefine the meaning of disability (Swain 1999, (Watson 2002).

### **C. Models of Disability Theory**

Disability theory can be seen to clearly divide into two schools of thought. The **individual or medical model** of disability and the **social model** of disability. The different aspects of society that formulate our social perceptions of disabled people, and our practice towards them, are heavily influenced by these models of disability.

## I. Individual Model of Disability

As the name implies, the individual model of disability is based on the premise that the primary person affected by the disability, and responsible for overcoming it, is the disabled individual him/herself. It falls in line with the 'personal tragedy theory' which suggests that the person is a tragic victim, and that 'disability is some terrible chance event which occurs at random to unfortunate individuals' (Oliver 1996:32).

It would then, perhaps, logically follow that the other fundamental point to be made about the individual model of disability is that 'it sees the causes of this problem (disability) as stemming from the functional limitations or psychological losses which are assumed to arise from disability' (Oliver 1996:32). That is, from the individual's 'coming to terms' with the disability, and not from the functional obstacles or psychological stresses that society and the environment may present.

The reasoning of this model follows that the essential route to 'recovery' from the disability involves both psychological and physical rehabilitation and retraining of the individual. Psychological rehabilitation refers to the processes of dealing with the 'tragedy' in terms of accepting this fate, and absorbing it and incorporating it into the person's new 'disabled' self image. Physically, or physiologically, the rehabilitation path is the one that would provide the technical assistance and aid in training the person to adjust to the disability in their daily dealings with the surrounding environment, and perform as 'normally' as possible.

It is of note that this model collapses the distinction between the 'impairment' and the 'disability', assuming that the former is immediately followed by the latter, and that the source of both is the person with the impairment. Thus, it not only focuses on the individual as the primary player, but also singles out the impairment, the 'abnormality' which has brought about the disability and the subsequent functional limitations. This impairment is seen to affect the individual's capacities in

general, and 'the 'disability' becomes their defining characteristic' (Barnes 1999:21). Consequently, the disabled person is perceived as dependent and in need of care. Furthermore, they are considered to be too traumatised by the physical and psychological effects of the disability to be able to attain a reasonable quality of life for themselves on their own (Oliver 1996).

This has been the basis of social welfare policies and social care practices developed by social services in the nineteenth century and most of the twentieth century. It has also evolved over the years and tapped into advances in medical technology and administrative theory to spawn the medical model of disability, and the administrative model of disability.

### ***Medical model***

The medical model of disability borrows from the individual model by presuming that the disabled person is 'largely inert: acted upon rather than active' (Barnes 1999:26) and primarily focuses on the disabled person as a patient. Similarly, the focus is solely on the impairment, and the technical skills of the medical field are drawn upon to provide treatments or surgeries that may correct it. As with the commonly accepted doctor-patient relationship, decisions regarding the impairment, and the best interests of the patient, are made by the doctor.

The 'patient' role in this model assumes that patients are victims of accidents or diseases. In cases where the impairment is found to be beyond 'cure' or any additional correction, disability is seen as a chronic and even terminal condition, and psychological theories of dealing with these are imported into the study of disability (Abberley 1993). Another similarity between individuals who are chronically ill and disabled people is that they become experts on their condition, and their opinions are not always heard. Finkelstein has argued that the one social construction of being disabled is equivalent to being 'socially dead' (Finkelstein 1993):35).

The disabled person is seen primarily as being passive and dependent, segregated from the other 'well' and 'normal' members of society. An 'impaired role' is difficult to leave, but is also powerful enough to create a dependence in disabled persons that makes them reluctant to relinquish the role and battle to be accepted as 'normal' when their functional limitations persist (Barnes 1999).

### ***Administrative model***

The administrative model refers to the social welfare services that were intended to compensate for the medical model's non-holistic approach and extend the rehabilitation issues to include those of psychological and social well-being and the details of the disabled individual's daily life. 'In this structure the medical model provides the framework for rehabilitation interventions and a welfare model of disability guides personal-care services' (Finkelstein 1993):37).

Finkelstein is referring to social and health workers whose duties included home visits, recommending modifications in the home and environment to facilitate movement and 'independent' living, and training for the disabled individual and his/her immediate family to deal with the disability. The model has effectively shifted the professional responsibility of the disabled individual's well-being from the medical to the social or community-based services, without truly changing 'the basic approach of intervening in the lives of disabled people' (Finkelstein 1993):15).

In this organisational case study of visually impaired children in Lebanon, the influence of individual medical and administrative models is clearly seen in the institution and the views of the service providers and families.

## II. Social Model of Disability

The social model of disability emerged years after the individual model approach had infiltrated the policy and practice concerning disabled people, and through it 'the meaning of disability was turned on its head' (Barnes 1999:28). Its development was shaped by activists and scholars linked to the disability rights movement in the 1970s, 80s and 90s.

The social model shifts the spotlight and burden of disability from the impaired individual to the restrictive barriers in the surrounding society. The main premise here is that the impairment in itself is not the cause of disability, but that the social and environmental barriers that meet this impairment are disabling. The social model formalised the distinction between impairment and disability (Shakespeare 2006). For example, a person with a physical impairment is disabled by the design of the physical environment and the obstacles that it places before him/her. Similarly, a sensory impaired individual is disabled by his/her limited access to communication and information that society presents in only written or oral formats.

Another fundamental shift that the social model brought about is that it moved the disabled individual from the sidelined margin that he/she had been traditionally assigned to, and placed him/her back into the central canvas of society. Disability was transformed from an individual matter to a collective one (Barnes 1999).

Through this model, 'impairment' and 'disability' have been redefined to read as follows:

*Impairment:* lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.

*Disability:* the disadvantage or restriction of activity caused by a contemporary social organisation 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, 1976:3-4 – In Barnes 1999:28)

As such, this new perspective has raised new questions as to the nature of 'disability' and its real causes (Oliver 1996). The social model has repeatedly reversed the framework of the individual medical model to illustrate that it is the predicament or role that the impaired person has been put in, and not the impairment, that is disabling. 'The 'reality' of impairment is not denied. Instead, the 'emphasis is on the ways in which society goes out of its way to render people with impairments dependent and unable to engage in many social and economic activities' (Barnes 1999:78)

It is argued that physical and working environments are designed for non-disabled individuals, and are consequently riddled with obstacles that prevent the disabled person from performing as efficiently as their non-disabled peers. In addition to these restrictions, the disabled person has been traditionally typecast as dependent and passive, and is thus not perceived as being reliable or capable of holding a job and performing at a profit-making level. Thus, 'the economic and social barriers that disabled people face are so pervasive that disabled people are prevented to ensuring themselves a reasonable quality of life by their own efforts' (Oliver 1996:65).

The social model, therefore, defines disability as 'all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on' (Oliver 1996:33).

By emphasising the disabling nature of all things external to the disabled person and his/her impairment, the social model has argued that the impairment becomes nothing more of a differentiating factor than race or gender or skin colour. Consequently, it has asserted that individuals with impairments are therefore as 'normal' as any of their non-disabled peers. And although this has had large repercussions on issues such as policies and rights which are meant to promote or maintain social equity within society, it has also withstood criticism from disabled

persons themselves who feel that the model was 'normalising' them to the point of denying them the experience of their own bodies, and impairments. (Morris 1991)

Supporters of the social model would argue that the model is not a social theory that attempts to explain disability in its totality, but that it has introduced a different perspective that has shattered the commonly held causal relationship between impairment and disability (Oliver 1996). By doing so, the model has questioned the merits of the medical model and the endless quest towards accepting intrusive and untested attempts on one's body to 'correct' impairments.

By liberating the individual with the impairment from the burden of the disability, the social model has also blurred the lines that segregated him/her from the rest of society, and denied him/her their social obligations and rights. As Vasey phrased it: 'The social model is not about showing that every dysfunction in our bodies can be compensated for by a gadget, or good design, so that everybody can work an 8-hour day and play badminton in the evenings. It's a way of demonstrating that everyone - even someone who has no movement, no sensory function and who is going to die tomorrow - has the right to a certain standard of living and to be treated with respect' (Barnes 1999: 31).

Above all, the social model has drawn on theories of oppression and injustice, similar to those relating to race or gender, and in doing so has raised the question of discrimination against difference. It has placed all commonly held perceptions and beliefs about disability to the test. It has forced a scrutinising investigation into 'perceptions of normality, and social exclusion and inclusion - particularly with reference to the social organization of work, the economics and future of welfare, and the politics and culture of interdependence and difference' (Barnes 1999: 213)

There is, in addition, yet another model of disability – the social constructionist model.

### ***Social constructionist model***

The social constructionist model shares a similar philosophy to the social model; it acknowledges that disability has a social dimension but argues that all that is required to resolve it is 'the education of the general public regarding ... disability, with a view to changing their attitudes' (French 1993):18)

This model redefines disability as a social construction, and hence focuses on the way that it is defined and perceived. For example, if the disability is defined as an individual problem, and the disabled person is perceived as a tragic victim, then he/she will be treated as such in social settings. By its definition, the social constructionist model would assert that such issues can be rectified by working on people's attitudes. However, there has been ample evidence from awareness campaigns that working on attitudes alone is not sufficient to remove the obstacles that disable impaired individuals in their daily lifestyles. There are real obstacles in the physical and legislative environments that cannot be changed solely by changing attitudes.

This inadequacy of the social constructionist model led disabled people to define disability as a social creation, not just an attitudinal problem that was created by all physical and social frameworks that make up society (Oliver 1993).

### **III. Analysis & Critiques of the Models of Disability**

Needless to say, each model has implications for the representations of disabled persons in society, which in turn, influence societal attitudes towards them, the services that are designed for them and the opportunities that are offered to them in general. Each of these also impinges on the personal and collective definition of a disabled identity.

The medical model, as it has been described in the previous section, constructs the disabled person as someone who is unwell and in need of care and attention to get better before he/she can fully rejoin society. It propagates an expert-client model between the disabled person and medical professionals, educators, social workers, employers and policy makers, simultaneously implying that all non-experts will not know how to best deal with them. These can be summarised as follows:

<i>Perspectives</i>	<i>Observation of Disability as:</i>
Medical system	Diseases, defects, malfunctions, impairments, treatment
Economic system	Lack of economic resources, inability to pay, poverty
Labour market system	Working disability, inability to engage in gainful activity
Legal system	Legally incapacity, lack of rights / duties
Rehabilitation system	Support / correction of functional incapacities
Education system	Learning difficulties, low education level
Art system	Ugliness, defective body

(Michailakis 2003): 223)

As a consequence, services are designed in such a way as to provide the disabled persons with whatever compensates for their incapacity in whichever realm. 'Allowing the individualised notion of disability to prevail allows policymakers and employers to conceptualise disability as a misfortune that some people encounter, which legally only requires them to compensate by extending the reach of their services.' (Donoghue 2003): 203)

Aside from ascribing problems to the disabled person him/herself, these perspectives also breed stereotypical disabled identities. The manifestations of these stereotypical social constructs have been outlined in detail in the previous sections.

It is precisely this discrimination that was the moving force behind the development of the social model of disability, which Finkelstein and Oliver described as a response to the oppression faced by disabled persons as a result of this discriminatory and imbalanced perception of disability and

disabled persons (Finkelstein 1993); (Oliver 1996). 'In this context, the social model harbours a number of virtues in redefining disability in terms of a disabling environment, repositioning disabled people as citizens with rights, and reconfiguring the responsibilities for creating, sustaining and overcoming disablism.' (Humphrey 2000): 63)

Despite critiques of the social model, the invaluable contribution it has made in representing and advocating for this shift is beyond debate. It continues to face various challenges, however, most of which seem to come from within disability studies and disabled persons' groups. At the forefront of the criticisms of the social model is its steadfast insistence that the disability is a result of external, social barriers so that the existence of the impairment is practically overlooked, as indicated earlier by Morris. Others would agree that 'really their problems lie in the fact that they have made the phenomenon of disability disappear. It is in this sense that the social model of disability might be construed as an 'anti-social' model' (Dewsbury, Clarke et al. 2004): 153). In response to this, other sociologists have asserted that 'what has been obscured by the shadow of the social model of disability... is an understanding that disability *only* comes into play when the restrictions of activity experienced by people with impairment are socially imposed, that is, when they are wholly social in origin. Such a social relational view means that it is entirely possible to acknowledge that impairments and chronic illness directly cause *some* restrictions of activity. The point is that such non-socially imposed restrictions do not constitute 'disability' (Thomas 2004). The focus on eliminating social and environmental barriers has also been considered quite urban-centric; 'outside the city, the social model seems harder to implement. Wheelchair users are disabled by sandy beaches and rocky mountains... It is hard to blame the natural environment on social arrangements' (Shakespeare 2006): 45).

In its activist stance, the social model has also instigated a subtle 'us and them' dichotomy between disabled and non-disabled persons. Some have concluded that 'the social model in practice is grounded upon a dubious premise – namely the antinomy between 'disabled' and 'non-

disabled' people' (Humphrey 2000): 81). As such, it implies a shared disabled identity among all disabled persons when this is not necessarily the case. That is, the social model's movement did not account for the diversity of desires and self-perceptions of disabled persons (Shakespeare 2006). For example, 'from the 'inside', there are deaf people who are classified as disabled in legislation and by society, but who repudiate the disabled identity on the grounds that they constitute a distinct linguistic and cultural minority' (Humphrey 2000): 65). Additionally, it has been repeatedly pointed out that 'many disabled people do not want to see themselves as disabled, either in terms of the medical model or the social model. They downplay the significance of their impairments, and seek access to a mainstream identity' (Shakespeare and Watson 2002): 20). It has also been argued that the social model movement was pushed forward through the efforts or activism of a few and that it is not representative of all disabled people (Shakespeare 2006). 'Zola has further pointed out that many people with disabilities are isolated from the outside world, making it difficult for them to participate in such a movement. This inevitably raises the question of whether the social constructionist paradigm allows for the redefinition of a group of people through the actions of a few' (Donoghue 2003): 206).

Furthermore, within this dichotomy is an aggressive state of lobbying and demand from disabled persons to non-disabled persons, that holds weaknesses of its own. 'Key among (the social model's) deficiencies is the potentially idealistic notion that the non-disabled majority will not resist a redefinition of disability at the cost of its own power and dominance' (Donoghue 2003): 207).

These critiques of the social model all seem to refine and develop it further. As one author put it, the critiques, weaknesses and deficiencies 'do not entail the demise of the social model as such, but they do pose creative challenges to it.' (Humphrey 2000): 81) Main proponents, and current critics, of the social model would agree that there is a need to develop the model further to learn from the experiences of the past thirty years since its inception and to respond to the changing

context – ‘A model which was developed in the early 1970s no longer seems as useful at the beginning of the twenty-first century’ (Shakespeare and Watson 2002): 23).

The social model needs to be re-categorised as it really is and not as it has been perceived and used. It is not an explanatory model, nor a definition or academic paradigm, nor was it intended as a research method. It should, however, remain in place as a practical tool, and a powerful organising principle (Thomas 2004); (Dewsbury, Clarke et al. 2004); (Beckett 2000). It needs to be reclaimed within its original framework, and be a launching pad for other areas of research and development. At the heart of it all, the social model brought disabled persons to the forefront as citizens and rights-holders. ‘We can say, ‘Yes, of course impairment causes some restrictions of activity – but these are not what is of interest in studying and combating disability’. Disability is a form of social oppression on par with other forms of oppression in our society associated with gender, race, class and sexuality’ (Thomas 2004): 581). This has instigated the inception of other complementary or additionally elaborative theories, as well as bringing disability considerations or applications to other sociological frameworks, such as systems theories, capabilities frameworks (Burchardt 2004), resistance theories (Gabel and Peters 2004) and others, which is precisely what could bring the essential aspects of the social model into contemporary applications and movements for social change. In developing the social model further, it has been suggested that ‘more attention needs to be given to further developing theory-level responses to problems like the persistence of disabling attitudes, and to the possibilities and the problems which may derive from working with non-disabled people, so that the model continues to be of practical use to the wider disabled people’s movement’ (Tregaskis 2002): 467).

In Finkelstein’s essay “*The Social Model of Disability Repossessed*” he aptly brings this point forward by stating that the model is a springboard for seeking change in society and that ‘for (him) *repossessing* the social model of disability means searching for openings in the structures of

society where we might effectively contribute with others in the restructuring of society so that it is neither competitive nor disabling for all people.' (Finkelstein 2001): 5).

This thesis examines the lives of a group of disabled children to explore their experiences of disability, and to gain insight to ascertain aspects of social policy that could enhance their prospects and quality of life. The influence of the medical and social models of disability on policy and practice is evident in this setting.

## **D. Rights, Needs & Oppression**

A contextual understanding of disability can be gained from a rights discourse. Whether at the personal, legal or moral level, the interpretation of these rights and their translation into legal or social practices can shape the social context of disability. Consequently, the rights focus provides one framework for working with disabled people to change social practice and attitudes. That is, rights in terms of equality, and equity – concepts which lie at the core of the human rights struggle (Belanger and Garant 1999).

The rights discourse spans social issues as formal as citizenship and discrimination, and as daily and personal as needs and participation. The disability literature has consequently undertaken in-depth analyses of specific constitutions or declarations as case studies being explored from the perspective of disabled people. Rights have emerged in the literature either directly or indirectly through accounts of personal or community experiences of disabled individuals, and the hidden oppression that was involved. The following sections will present some of these issues.

## *Exclusion and access*

Oliver (Oliver 1996) describes citizenship as 'a shorthand device for talking about the relationship between individuals and their societies' (Oliver 1996:44). As such, it delves into political, social and civil rights, and provides a measure of the social integration of individuals and groups into society. Consequently, examining the extent to which people with disabilities are granted these rights is directly linked to their social participation or, conversely, their exclusion.

'Exclusion' appears consistently in the context of disability as an imposed situation. It is used to refer to all forms of exclusion that face disabled people – physical, social, professional and so on. It relates to inequality of access to these circles, and to consequent discrimination. Charters and constitutions attempt to regulate the interactions of its citizens by bestowing equal rights upon all of them, including disabled people. The reality of their implementation, however, illustrates the exclusion of disabled people on many counts.

The previous sections have drawn out the social construction of the disabled person, from the labels he/she is given, to their representations as social members or economic players. All of these have fallen within the 'abnormal' or 'special' category, and they have generally been unfavourable to the disabled person. In practice, these have either served to exclude the disabled person when no changes are introduced to accommodate him/her, or have compounded their status as 'special' when they were.

To illustrate – the simplest political act that a citizen can undertake in a democratic community is that of voting, and yet the disabled person is often denied this political voice for reasons as basic as access. There are often limitations of physical access to the relevant offices and bureaux, and access to the necessary information in a format other than written text (Oliver 1996). This does not deny the person his/her civic status, but prevents him/her from exercising the power that this entails. This produces a vicious cycle which leads to more decisions being made at a community

or national level that do not include the needs or demands of disabled people. Consequently, it becomes an act of exclusion. In fact, Barnes, Mercer and Shakespeare agree that 'social exclusion is never more evident than in the restrictions placed on mobility and access by a poorly designed built environment' (Barnes 1999:117).

The issue of access – to information, transport, buildings and other social facilities – touches upon enabling disabled people to empower themselves, while simultaneously creating avenues for additional discrimination. For example, the law in several countries enforces equal opportunity employment, yet issues such as access create difficulties that discourage or hinder the employment potential of people with disabilities (Oliver 1996). The special provisions required for employees with disabilities are seen to lessen their productivity and reliability, and consequently their employability. This situation contains several contradictions. First, that disabled people are required to act 'normally' within the facilities provided in order to be perceived as qualified and independent, and yet the facilities are designed with inherent obstacles that exclude them. Secondly, that the laws or legal frameworks that are constructed to include all citizens do so with a non-disabled person in mind, and manage to exclude disabled people. These barriers are 'embedded in policies and practices (that are) based on the individualistic, medicalized approach to disability' (Barnes 1999:168). In that sense, it has been argued that they are, in fact, dependency-creating practices and policies (Barnes 1999:145).

The obstacles that disabled people face in attaining social and financial independence affect their contribution to the 'social wealth' of the society. This, Finkelstein would argue, adds to their social marginalisation, and naturally affects their say in issues concerning society (Finkelstein 1993):12). Hence, an impasse is created that plunges people with disabilities into a downward spiral that renders them progressively more and more dependent on outside help, welfare services and the like, and moulds them into the 'disabled identity' that society perceives of them, as indicated in previous sections. Removing these obstacles requires more than increasing the control of

disabled individuals over material resources and the quality of services. 'It requires a fundamental reappraisal of the meaning and hence medicalization of disability' (Barnes 1999:168), and a discerning look at the physical and social environments that disable people with impairments, and prevent their complete social integration and participation. The empowerment of the disabled person should also enter into this process since 'a key dimension of disability is the extent to which a society removes barriers and enables people to participate, regardless of their individual differences' (Shakespeare 2006): 61).

These issues bring to light how exclusive all-inclusive laws and policies can be, either in their design or in their implementation. A specific convention addressing the rights of children (Convention on the Rights of the Child (CRC), 1989) dedicates one of its 54 articles to disabled children. This article reads as follows:

### **Article 23**

1. *States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.*
2. *States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.*
3. *Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development*
4. *States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.*

(UN 1990)

Once again, it is understood, and stated in the CRC, that all its articles include disabled children. That an article is dedicated to them in some ways indicates their special status and needs.

However, as can be seen from this one article, its main focus lies in a medicalised perception of service provision, pointing to preventive and rehabilitative services, and does not sufficiently deal with the issues of attitudes and discrimination that would prevent the child's social integration and participation. Furthermore, the implementation of the CRC itself has been criticised as not always being suitable to the child's situation or in his/her best interests, as will be discussed in more detail in the following chapter.

Another UN convention that addresses children with disability is *The Salamanca Statement and Framework of Action on Special Needs Education* (UNESCO 1994). The basic principles of the Salamanca statement are aptly summarised as follows:

***We believe and proclaim that:***

- *every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning,*
- *every child has unique characteristics, interests, abilities and learning needs,*
- *education systems should be designed and educational programmes implemented to take into account the wide diversity of these characteristics and needs,*
- *those with special educational needs must have access to regular schools which should accommodate them within a childcentred pedagogy capable of meeting these needs,*
- *regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system.*

*(UNESCO 1994):viii)*

These embody the concept of inclusion, that is of an inclusive society, within the scope of education. However, in its work to assign a special status to the disabled child, such declarations propelled a dialogue of 'special needs' that sometimes worked against disabled children. This is discussed in the following paragraphs.

## *Rights versus needs*

*'All children of the same age were assumed to be the same for purposes of instruction, despite the fact that they are not.'* (Vlachou-Balafouti 1999):163)

The 'special needs' school of thought referred to all the different, and additional, needs of children and adults that needed to be catered for beyond the 'normal' services and facilities provided in society. As Stubbs points out in her analysis of Article 23 of the CRC, the article 'refers to concepts such as 'special care' and 'special needs' without defining them ... the priority needs of disabled children are not special, they are basic; disabled children need food, shelter, love and affection, protection, education' (Stubbs 1997):1).

It could be argued that the 'special needs' discourse contributed to the marginalisation of disabled persons rather than to their inclusion. Needs-based interventions also appeared as a deeply entrenched form of the individual and medicalised models of disability, in specialised services and professions that address the needs, the impairments, and not the individual. Oliver (Oliver 1996) argues that 'professionalised service provision within a needs-based system of welfare has added to existing forms of discrimination' as well as creating 'new forms of its own' such as professional practice based upon invasions of privacy and a discriminatory language of paternalism (Oliver 1996:75-6).

In the advocacy context, issues such as social exclusion or discrimination of disabled people may appear as part of the 'special needs' discourse, and are not linked to the concepts of and struggle for human rights. Sweeping these into the 'needs' discourse implies that they are difficulties that relate to the individual, rather than to the social, economic and political relations in society, and that they can be overcome by 'technical solutions' (Armstrong and Barton 1999):212). That is, they do not fall into a discourse of social attitudes or discriminatory policies. Instead, it is argued that the individual lacks certain traits, has special needs, which when met with the appropriate

technical treatment, would allow for their full and complete integration into society. Consequently, a 'needs' argument aligns rationality of the law, and of governance, with the state, and bestows upon it the role of mediator and problem solver for vulnerable or dependent groups. This is considered by some to undermine the capacities of disabled persons, and is thus 'disempowering because it focuses attention away from the possibility of individuals, groups and communities taking responsibility for undertaking action themselves to bring about change' (Armstrong and Barton 1999):212).

It is arguments such as these that have urged that there be a shift from 'needs' back to 'rights'. The rationale being that arguing from a "human rights' position is fundamentally different from a 'needs' position because it challenges power relations, structures and practices in society which are held together and sustained by the state' (Armstrong and Barton 1999):212).

It also stresses the individuality of needs and the universality of rights. Just as Stubbs pointed out that the basic needs of all children are the same, claiming that some members have 'special' needs is equivalent to saying that their needs are not average, or normal. Although this may seem as an attempt to cater to them equally, it inadvertently categorises them as different, and consequently segregates them.

This thesis adopts a rights based perspective by grounding its analysis of Lebanese legislation and social services in basic rights principles of universality, inalienability, indivisibility, interdependence and participation.

## *Social oppression*

While discussing the importance of definitions, Oliver presents his case by making the following distinction: 'If disability is seen as a tragedy, then disabled people will be treated as if they are the victims of some tragic happening and circumstances. This treatment will occur not just in everyday interaction but will also be translated into social policies which will attempt to compensate these victims for the tragedy that has happened to them. Alternatively, it logically follows that if disability is defined as social oppression, then disabled people will be seen as collective victims of an uncaring or unknowing society rather than as individual victims of circumstances. Such a view will be translated into social policies geared towards alleviating oppression rather than compensating individuals.' (Oliver 1993:62)

Oppression has been described as consisting of five dimensions: exploitation, marginalisation, powerlessness, cultural imperialism and violence (Barnes 1999:81). All of these appear, in one form or another, in the case of the disabled people. Situations describing marginalisation and powerlessness have been extensively described in this paper, and are also reflected in Oliver's statement above. The striking dimension that rings throughout the disability discourse is that of cultural imperialism, or hegemony. That is, the dominating influence of one group over another, where the dominant's views and values are considered inherent or commonsensical. And 'disability is infused with 'able-bodied' norms and values' (Barnes 1999:82) which directly or indirectly affect and control numerous aspects of the lives of disabled people. These have been highlighted in the discussions of the disabled 'spoiled' and stigmatised identity, and also appear in the preceding discussion on exclusion and special needs. These all point to forms of discriminatory prejudice. Morris explains this as follows: 'Prejudice is associated with the recognition of difference. In theory 'normal' could be a value-free word to mean merely that which is common, and to be different from normal would not therefore necessarily provoke prejudice. In

practice, the word is inherently tied up with ideas about what is right, what is desirable and what belongs.' (Morris 1993):101) These all reflect aspects of cultural imperialism, and of oppression.

These forms of internalised oppression are so greatly a part of disability that it is consistently argued that the key to understanding disability lies in understanding the oppression that accompanies it (Oliver 1996; Barnes 1999). It is also considered the only way forward, towards improving the status of disabled people – 'in terms of creating radical and new forms of disability representation, (it is important) ... to acknowledge that it is both the organisation of economic production and the projection of (non-disabled) negative desire, which contains disabled people within oppressive cultural representation' (Hevey 1993):118).

Other minority groups are similarly oppressed into a social role that is subordinate to the hegemonic status quo. The more obvious examples are those relating to race and gender. Social oppression of women and members of certain ethnic groups has gone through all the levels of discrimination listed above. The main difference between them and disability is that 'impairment, by definition, is functionally limiting, whereas sex and 'race' are not' (Barnes 1999:79). The point to be made here does not relate as much to comparing the respective oppressive situations, but to allude to the 'double jeopardy', or multiple, compounded oppression that a person who fits into more than one of these roles may face. That the different social labels may actually work against each other, and cancel out the individual's rights even further.

A study conducted by a non-governmental organisation in Lebanon to determine its main beneficiaries showed that it was the disabled men who participated in their activities. This then appeared as a natural outcome since the organisation could only reach disabled individuals in public and social settings, which would not include disabled women who are generally more secluded than their male peers (Lakkis 1997).

The prevailing attitude to gender in Lebanon and in much of the Arab world considers the man as the main bread-winner, and this has hindered young disabled females from being accepted into schools, or from being given paid employment. The possibility of marriage for disabled girls is frequently dismissed because of the disability, whereas it is found acceptable and natural for a similarly disabled man to marry and raise a family (Fahd, Marji et al. 1997)

Morris also found that the image of women is generally linked to motherhood and heterosexuality, whereas that of disabled women is seen as passive, weak, dependent, and without children (Morris 1993). The same can be said to apply to disabled members of ethnic groups, and to disabled children. These individuals are subject to several forms of discrimination, all of which work towards denying them their rights further.

### *Other perspectives on rights*

Although there are sufficient experiences to support viewing disability as oppression, it has been argued that doing so 'leads the minority group into taking up a victim position' (Shakespeare 2006): 79) which does not celebrate impairment or disability, a position from which resistance and inducing change would be difficult.

In his study of the Swedish welfare system and the provision of special rights for the disabled individual, Gustavsson (Gustavsson 1999) discusses the identification of two different perspectives on disabled people's rights – a 'rights-disability' perspective, and a 'rights-ability' perspective. The former indicates that 'special rights presuppose a certain helplessness in the form of lack of competence and autonomy' and the latter is one where 'competence and autonomy are seen as possible to achieve by means of the special rights' (Gustavsson 1999:149).

This distinction appeared in his study of intellectually disabled persons, whose perspective he describes as “experience-near”, as opposed to the “experience-distant” perspective of service providers, the welfare state and professionals. The experience-distant group followed the general framework that was placed for the support of “weak groups”, where the provision of support was associated with the existence of a permanent special need. As such, their system was built on the helplessness of disabled persons, and on the support they would require to achieve certain tasks.

The experience-near group, however, redefined ‘ability’ into a formula that not only consisted of the ‘difficulties of the task’ and ‘personal skills’, but also included the support necessary to complement personal skills and achieve the task (see Box 1). Consequently, ‘disability’ was transformed into ‘ability’ with the necessary support. Such was the ‘rights-ability’ perspective where rights were associated with ‘opportunities to achieve conditions of everyday life equal to those of other citizens’ (Gustavsson 1999:154).

**Box 1: Redefining ‘ability’**

Common-sense understanding of ability:

(the difficulties of the task) + (the person’s skills and dispositions) = Ability

The alternative understanding of ability:

(the difficulties of the task) + (the person’s skills and dispositions) + (a *taken-for-granted support*) = Ability

(source: Gustavsson 1999:151)

In their discussion of equity and inclusion, Kerzner-Lipsky and Gartner define autonomy as follows:

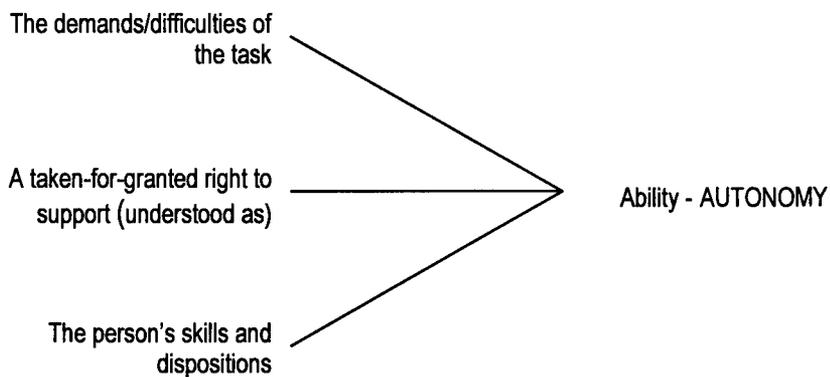
Autonomy is something granted to persons who are valued. For individuals to be autonomous reflects acceptance of three interrelated beliefs. They are:

1. a statement as to the *right* to control one’s own life;
2. an expression of belief in the individual’s *capacity* to do so; and
3. a recognition of the *benefits* to the individual of doing so.

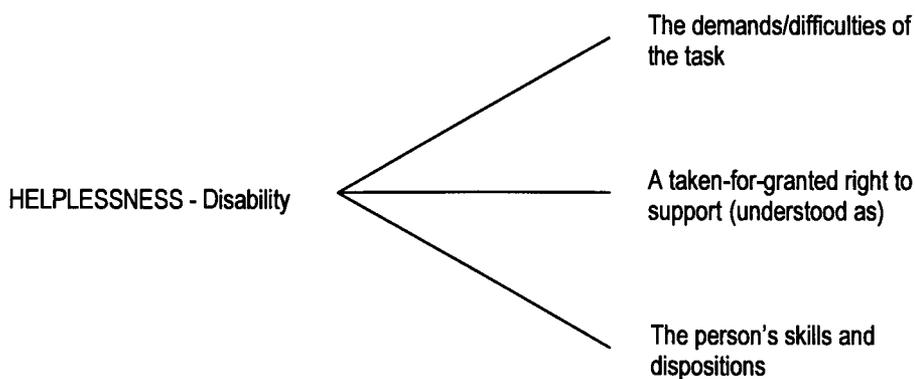
For persons with disabilities, autonomy is limited by at least three factors. These are:

1. the limitation inherent upon the *impairment*;
2. broad societal *attitudes* toward persons with disabilities; and
3. the nature of current *human services practices*.

(Kerzner-Lipsky and Gartner 1996):152)



*Experience-near, rights-ability perspective*



*Experience-distant, rights-disability perspective*

(Source: Gustavsson, 1999:156)

It is indeed such approaches, and the lessons learned from previous statements and conventions, that informed the drafting of the UN Convention on the Rights of Disabled Persons which was adopted by the United Nations General Assembly on December 13, 2006. This convention is the first to clearly and directly address disabled persons as rights-holders, stressing the need for 'a paradigm shift' in the attitudes and treatment of people with disabilities – from seeing persons with disabilities as objects of charity to considering them as individuals with human rights' (Lansdown 2006).

## E. Approaches to Working with Disabled Persons

In this section the different contexts based on different approaches that have been designed to work with disabled persons will be reviewed. These can be broadly categorised as institutionalisation, integrative programmes and inclusive programmes. The framework supporting such approaches differs and consequently affects the roles of the professional carers, family, community members and the disabled persons themselves.

Table 1.1 offers a brief description of each of these settings versus the role of disabled children.

	Child	Environment & Community	<i>In Lebanon...</i>
<b>A</b> Institutions	<ul style="list-style-type: none"> <li>The child's special needs are addressed in a setting that is separate and specialised.</li> <li>The child is segregated and taught that he/she is different</li> </ul>	<ul style="list-style-type: none"> <li>An artificial environment is created for the child to be able to live in with his/her disability</li> </ul>	<i>Most of these were originally set up by religious institutions, thus enthusing it with a grossly charitable philosophical approach.</i>
<b>B</b> Integrative programme	<ul style="list-style-type: none"> <li>The child is taught to fit into the existing structure of the environment</li> </ul>	<ul style="list-style-type: none"> <li>The environment accepts the child but does not adapt to his/her needs</li> </ul>	<i>'Integration' can be seen in some CBR programmes that were set up in communities where little to no supportive health services could be found. That is, in refugee camps and in the poorer communities existing on the fringe of urban areas. It otherwise appears in inconsistent mainstreaming attempts into mostly private schools.</i>
<b>C</b> Inclusive school	<ul style="list-style-type: none"> <li>The child's needs and capacities are assessed, and programmes are developed that best suit them.</li> <li>The traditional structure of institutions and society is seen as the problem.</li> </ul>	<ul style="list-style-type: none"> <li>The society and environment learns more about the child's needs and capacities and learn to adapt to them.</li> </ul>	<i>A handful of public and private schools have taken on this approach in more recent years. The schools have implemented this in different manners, with little room for comparison or evaluation.</i>

*Table 1.1: The Child and the Environment in three different contexts*

The detailed organisational case study was conducted in type A, and there was additional fieldwork in type B and C settings.

## I. Institutionalisation

The practice of institutionalisation dates back to the early years of asylums and quarantines. Aside from its rehabilitative aspects, it was also considered necessary means for containing 'deviance' until such a time that it has been treated and the person is allowed back into society. As mentioned earlier, this practice became more widespread for disabled people with the birth of the welfare culture influenced by the individual and medicalised models of disability. Consequently, the institutionalised person became a 'patient' or a 'client', with all the limitations of that role, and with all that those entail in terms of 'not being fit' to handle everyday life unaided.

Within their medical model philosophy, the main thrust of institutions has been defined as rehabilitative, yet 'while almost all (institutions) uphold the desirability of a restorative approach to rehabilitation, most of them follow an accommodative approach in practice' (Scott 1969): 90). They become lodging facilities for disabled persons, whose reintegration into society is considered cumbersome and a burden to the efficient operation of daily life in society, schools and employment. The act of entering an institution has also been perceived as symbolic, a process where 'the old self is removed and a standardized, institutional alternative is provided' (Barnes 1999:45). It has also been argued that this process does not only bring about a symbolic change in self perception, but an actual one as well, as a result of the operational standards adopted by those working in the institution; 'committed though many workers with disabled children are, this segregation is nonetheless accompanied by a tolerance of patterns of care which would not be accepted for non-disabled children' (Morris 1995): 83).

Institutionalisation has also largely fed into the social construction of a 'spoiled' disabled identity, and has also been designed along its lines. For example, 'historically, children with perceived impairments were socialized into low expectations of success in education and work

(consequently) their educational provision has been dominated by an ideology of 'special educational needs' and a segregated education system.' (Barnes 1999:104).

In this vein, another aspect of institutionalisation that has come under constant attack in recent years is that of segregation. Protection issues for children in special care have been of special concern where it has been argued that the children 'are often reliant upon other people for intimate care and assistance and this may mask abusive practices' (Read and Harrison 2002): 218). Segregation has also been greatly criticised for hindering the social integration of the disabled persons upon their discharge from the institution. The disconnection from their families and communities 'may predispose children to living in a state of drift' which not only influences them during their residence in special care as children but also 'their chances of undertaking positive transition to adult life beyond' their stay at the institution (Read and Harrison 2002): 218). It is felt that the artificial world that is created does not prepare the disabled person for the professional and social worlds that exist outside the institution walls, and perhaps even serve to keep him/her within them. However, it has also been argued by some that the environment in which disabled people find peers was much more conducive to their self-confidence and personal development.

Indeed, the arguments that have been made in favour of this approach usually refer to the incapacity of normal services to meet the needs of disabled people. That the care and protection that disabled children and persons need is optimally provided in these specialised centres and not in mainstream services. And although these still fail to address the segregated aspects of institutionalisation, there have been some cited positive experiences with the approach.

Mike Oliver and Sally French, in their own accounts of their time in such institutions, support some of the advantages of having been in such a place. Reading in between the lines of French's account (French 1993) reveals the insistence of the distinction between 'us' (disabled students) and 'them' (staff and non-disabled peers), but equally confirms the comfort at adapting games and

other social interactions among the visually impaired students. Anecdotes are recounted of when a group of Brownies or Girl Scouts would annually visit the special school for severely visually impaired children where French was sent, and where she and her friends would fumble through the games that were prepared for the day, as most of them required visual recognition. 'Whether the choice of these highly visual activities was a deliberate denial of our disabilities or simply a lack of imagination on the part of the adults, I do not know. Certainly we played such games successfully among ourselves, and as we were never seen in any other context, perhaps it was the latter. It was only on rare occasions such as these that our lack of sight (which had all but been forgotten) and the artificiality of our world became apparent.' (French 1993:72).

Oliver similarly describes his experience at Stoke Mandeville as one where 'the positive far outweighed the negative' (Oliver 1996:7). He not only credits his time there for his rehabilitation after his accident, but for much of his personal growth as well. 'The culture of Stoke Mandeville was definitely macho, and I was encouraged to undertake as much physical activity as I wanted' (Oliver 1996:7). It was also a place where the social dynamics between residents and professional staff played a positive role. 'I think I learned more about myself and personal relationships in the one year I spent there than I have subsequently...' (Oliver 1996:7).

## **II. Integrative programmes**

Integrative programmes have been defined differently over the years and by different agencies. In more recent years, especially due to the emergence of theories of inclusion, 'integration' has been used to refer to channels, schools or programmes that do not exclude the disabled person, and introduce them into the mainstream world in different forms and levels.

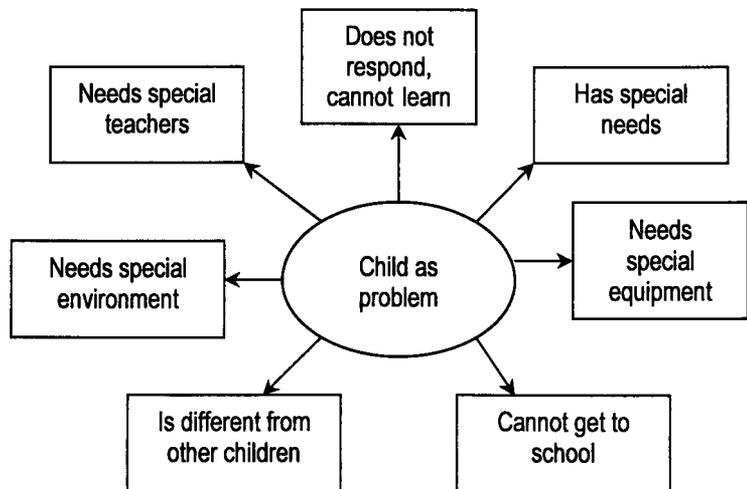
The Warnock Report (1978) has been cited as defining three main forms of integration into the mainstream:

- *locational* - special units or classrooms on the same site as an 'ordinary' school;
- *social* - where locational integration is complemented by social interaction;
- and *functional* - in which 'special needs' children join their peers on either a part- or full-time basis.

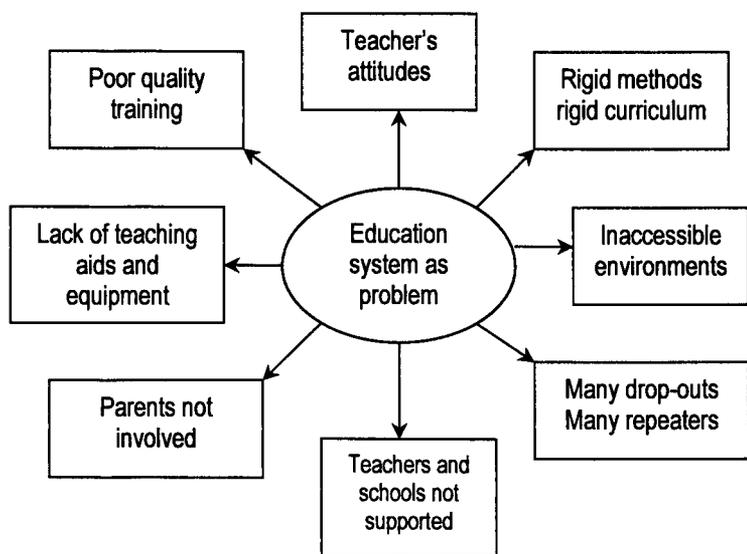
(Barnes 1999:105)

Though the nomenclature has varied slightly over the years, these remain the main categories of integration identified by practitioners today.

However, even amongst these levels of integration, students with severe learning difficulties or with sensory impairments are largely excluded, and remain in institutions and segregated schooling. It has been argued that there is a continual persistence of segregative or exclusionary practice within this approach – 'the exclusionary practices are still there: there is still labelling; exclusion shows



**Integrated Education**



**Inclusive Education**

**Diagram 1.1** – The main parameters of integration and inclusion in a school setting are compared and contrasted at the 'IDDC Seminar on Inclusive Education' held in Agra, India in March 1998 (source: EENET).

no sign of declining' (Thomas and Loxley 2001): 4).

Additionally, integration initiatives have not been found to necessarily adapt to the needs of disabled children and persons. The burden of succeeding in the process of integration is placed mainly on the disabled person, who is expected to find ways to fit into the system. Indeed, this is the distinction that is made between integration and inclusion – 'if 'integration' is about fitting the child into school, 'inclusion' presumes a 'whole-school' policy to suit all children, and one where there is full parental and community involvement' (Barnes 1999:109).

### **III. Inclusive programmes**

Inclusion can be considered the answer to the failings of integrative practices and did, indeed, arise as a response to them. It has been described as 'a strategy contributing towards ... promoting an inclusive society, one which enables all children/adults, whatever their gender, age, ability, ethnicity, impairment or HIV status, to participate in and contribute to that society. Difference is respected and valued.' (Stubbs 1998). As the actual process through which to practice non-discrimination and ensure participation, inclusion is steeped in a rights based approach.

The philosophical underpinnings of inclusion mirror those of the social model of disability where the dynamics towards inclusion involve the disabled person, the surrounding environment and society. Yet as the above quote illustrates, inclusion as a concept extends far beyond disability. The central factor, in fact, seems to be society, its members, and their levels of acceptance or exclusion. This would account for the fact that inclusion figures into the debate on rights and discrimination for all social groups or individuals who face social oppression, and that inclusive

initiatives are often driven by concepts of empowerment, awareness, equity and social justice (Armstrong and Barton 1999).

UNESCO has steadfastly advocated for inclusive education as a means for working towards its global *Education for All* initiative. It views inclusion as 'a dynamic approach of responding positively to pupil diversity and of seeing individual differences not as problems, but as opportunities for enriching learning.' (UNESCO 2005): 12). To that effect, it promotes the participation of children in learning, cultures and communities as a means to combat exclusion.

As a practical approach, the inclusion of disabled children and persons into schools, jobs and society not only entails removing obstacles from the physical environment, but also a re-education of people and their attitudes, and a reformulation of the disabled social identity and stigma. The measures required for such changes thus encompass a whole range of social players and arenas, and are complicated. It has been argued that this process could be made simpler through the early inclusion of disabled children into mainstream schooling. This would not only provide a broader spectrum of education for the disabled child, but foster friendships and relationships between disabled and non-disabled children which could pave the way to eliminating ignorance and stereotypes (Barnes 1999).

## **F. Conclusion**

This chapter has reviewed literature on constructions of disability and disabled persons. Though these perceptions have changed historically – from viewing the disability as entertaining, unproductive, deviant, immature and 'child-like' – these were all discriminatory perceptions with the focus being on the impairment as a deviation from the overall norm, and with roles being created into which such a deviance can be acceptably sidelined.

It could be said that the individual model of disability, and the related medical and administrative models, were the first attempts to re-integrate disabled people into society by attempting to diminish this disparity and 'restoring' them to more normalised levels of function and performance. These models, however, neglected to address the components of this disability that exist in society in terms of attitude, perceptions, acceptance and rights. They did not propose a broader view of all members of society, but rather created separate compartments where disabled persons remained, or were trained and rehabilitated to re-enter society.

The social model signifies a shift – one that distinguishes between the impairment and the person possessing it, and one that places the focus on the disabled person as an individual with rights, and asks society to reflect on the changes that it needs to make to adjust to this individual's impairment. Though the social model has been criticised for focusing on the physical environment, and not sufficiently considering the impairment, or issues related to gender, ethnicity, social attitudes and multiple identities, it remains powerful in its main premise that the impairment is carried by the individual but the disability is created by social barriers. For example, the discussion of language and labelling, and the suggestions for change, does not alter the reality of the existence of the impairment. It does, however, provoke society to shift their perceptions into an understanding of this reality rather than remain in the arena of the spoiled identity. At its core, the social model is a reconceptualisation, involving all actors at all levels in society to look into their contribution to disabling barriers and a consideration of their responsibilities to remove them. This is in line with rights based values that place the responsibility of adapting as per the needs of individuals on the state and society and not on the individual alone. This has the potential to transform the policy and the rationale of intervention programmes.

This thesis aims to identify the disability model that is adopted by Lebanese disability legislation and social service providers. It shall seek to address the gap in knowledge concerning the

influence of policy on social practice, and thus recommend policy criteria that could potentially bring about changes that empower disabled persons from a rights based perspective.

## **CHAPTER 2 – LITERATURE REVIEW ON CHILDREN & CHILDHOOD**

### **A. Introduction**

This chapter reviews the literature concerned with social theories of children and childhood as these are critical to the topic and framework of this thesis on the social construction of visually impaired children's identities in Lebanon. Classic and recent texts on the child, children and childhood illustrate the evolution of these concepts over time, and demonstrate how they have influenced both social constructions of childhood as well as public policies and programmes designed to address children. These assist in understanding how children are, conceptually, placed within their social contexts, the extent of their expected participation or involvement and how their roles and identities are defined. This led to the emergence of theories on the sociology of childhood that are relevant to the theoretical framework of this thesis.. This chapter outlines the main tenets of these theories and in doing so, also illustrates the challenges that they present to dominant perceptions of children and childhood.

## **B. Children within their Social, Cultural & Political Contexts**

The sociology of childhood is based on working with the child as an active subject, and has thus challenged dominant social constructions and perceptions of a universal childhood. Within this framework, children are also seen as a social group, and thus subject to forms of oppression within the social, policy or institutional contexts.

### **I. New Paradigms of Sociology of Childhood**

The 'new' paradigm of child sociology proposed by James & Prout (James and Prout 1990) suggested a set of principles that liberated studies of children from a traditionally narrow perspective. These were:

1. Childhood is socially constructed, that is, it is not 'natural' but shaped in crucial ways by the cultural and structural context.
2. Children's social relationships and cultures are worthy of study in their own right, independent of the concerns and perspectives of adults.
3. Children are not passive subjects of social structures and processes, but actively contribute to their own social worlds.
4. Childhood is not singular or universal, it is differentiated by factors like gender, ethnicity and class.

The paradigm has been long in the making. The above concepts can be seen to have been influenced by the early theories of Vygotsky in developmental psychology, who insisted on studying child cognition in the social context. Additionally, this 'new' paradigm can be seen to echo through most work with children in recent years, and has been slowly filtering through to the

established theoretical frameworks of the education sector. Just as Richards laments that “despite widespread discussion of the need for cognitive and developmental psychology to locate itself within a social and cultural context, only a minority of recently published empirical research even faintly considers this possibility” (Richards 1986):3). This has slowly changed in recent years, with more emerging research addressing children within their environments, but a review of published empirical research indicates that there is still a need for further work in this field. Indeed the areas that most inform and influence this paradigm of childhood have been through development and community work designed with children at the forefront.

‘One such approach has been conceptualised as the developmental niche, which identifies three elements within children’s environments that influence their development:

- **The physical and social settings they inhabit** – The family, social patterns, and organisation of their daily lives.
- **The culturally regulated customs and child-rearing practices** – Arrangements for care and education, attitudes towards play, discipline and training.
- **The beliefs or ethno-theories of the parents** – Goals and priorities for children’s development and views on how these can be achieved.

This construction has some limitations because children do not necessarily inhabit mono-dimensional environments but often move between different contexts at home and in school.’

(Lansdown 2005):12)

Incorporating the home and parents into paradigms of childhood shed light on previously overlooked aspects of children’s lives and capacities. Mayall (Mayall 1996) found in her study of children, that mothers incorporated external factors in their explanations for their child’s behaviour or health. She also found that the mothers viewed their children as active social agents, and were given roles in the household that were seen to be in line with their interests and capacities. More importantly, mothers realised the effect that experience can have on a child’s understanding and coping.

Mothers often look at their children holistically. Early childhood educators such as Indu Balagopal (Mobile Creches Association, India) and Judith Evans (The Consultative Group on Early Childhood) will point this out in a simplistic example: a mother does not play with the child and not feed him/her, she does not clothe the child without keeping him/her clean, and so on. When the child cries out, the mother attends with all the tools in her box as she looks at the child's holistic needs (Personal communication, ARC Regional ECD Conference, Larnaca, February 1997).

Time plays a big role in defining childhood, and it has been argued that childhood is distinguished by its specific temporal nature. James & Prout (James and Prout 1990) described this in two dimensions: 'time of childhood', where childhood was looked at as a period in the life course and ageing process; and 'time in childhood', which referred to children's everyday lives. It becomes progressively obvious that the adult constructions of childhood mainly address the time of childhood. The importance of childhood becomes entrenched in it being a period of transition, the stepping stone towards creating a productive, cooperative adult but portraying it as a time of innocence, purity, non-responsibility and fun (Hunt and Frankenberg 1990) sets it into the limbo of timelessness.

Additionally, the 'body clock' that runs during the period of childhood presents deadlines in the form of the stages of physical development of the child, where it is felt that specific needs must be met, and hence specific action must be taken. But the child's body itself, as with his/her age, imposes social rituals and 'rites of passage' that place the child firmly in the social canvas (van Gennep 1960).

The following sections will illustrate that the experience of childhood is created through a number of factors, but experienced only by children. Focusing on the child as the primary research subject and stakeholder educates us about childhood, about how it is constructed, and how this has, in turn, influenced systems and policies. Some sociologists of education argue that "the rethinking of

sociological theory to include children as a social group should serve as a basis for rethinking policies directed at the social positioning of children and childhood.” (Mayall 1996: 58) Others have also argued that “only by understanding the ways in which childhood is constructed by the heterogeneous elements of culture and nature ... will it be possible to take the field (of childhood studies) further” (Prout 2005): 44).

## **II. The Culture of Childhood**

James' (James 1993) study of childhood identities and the culture of childhood reminds us of the inherent rules and standards with which children treat each other and how the 'real' world occupies the children's impressions, reasoning and games. Children do not only view themselves as transitional figures yearning to become adults, but they also struggle with understanding the intricacies of the world they live in, and of their place in it. An example of this would be the intricate and elaborate war games that children in Belfast, Palestine, Beirut and currently Iraq developed during their years of living through a war. Children did not live in a fairytale existence divorced from their surrounding situation, and their games frequently mirrored what they saw – such as children setting up their own make-shift checkpoint – in their attempt to both understand what was going on around them and to find a place for themselves in it all.

Through language, children begin to learn – or possibly rebel against – expected social roles and behaviours. Though language and conversation are not the only medium through which children learn and understand the world around them, one cannot overlook that “learning how to participate in conversational contexts entails entering into the co-construction of participant folk-beliefs, accounts and narratives concerning childhood. Children are required to learn how to be ‘children’ as part and parcel of any other learning that might be said to be taking place” (Forrester 2002): 256).

The rules of conversing, with adults, with peers or younger children, all teach children about their social positioning in terms of acceptable content, responses, taking turns, and so on. In studying conversations of children, it becomes increasingly apparent that “the versions, narratives, ideas and conceptions of the ‘child’ that are children appropriate, and which may constitute elements of their identity, are embedded and reproduced in the talk of their peers, siblings, parents and other significant adults.” (Forrester 2002): 257).

The lexical categorisations and language used also reflect the social construction of childhood in different societies. It has been argued that “how we see children and the ways in which we behave towards them necessarily shape children's experiences of being a child and also, therefore, their own responses to and engagement with the adult world” (James and James 2004): 13). Language is one indicator of perceptions and attitudes, which underlies social, legal and educational initiatives for children, and thus also fashions children's perceptions of themselves and their roles.

Thus interactions with adults are naturally part of children's exploration of their surrounding environment. Adults frequently draw a distinction between themselves and children, and the implied understanding that children and childhood were defined by what adults and adulthood were not, as the following sections will illustrate. If this distinction and the outlined particularities of childhood could be considered sufficient to define children as a distinct social group, then studying the relations between the generations becomes a means towards better understanding children in context, and in the present time.

Mayall (2002) writes extensively about this in her discussion of generational relations. She indicates that children frequently forge a common bond in how they deal with ‘them’; the adults – “there is evidence that children do think of themselves as living within a common domain,

structured by adult behaviours and interests; they do form solidarity groups – to counter the power of adults at school, and to face up to family change and their own futures.” (Mayall 2002): 161)

These generational relations that construct childhoods are foremost influenced by the specific relations between children and parents. Reference here is not to the issues of nature and nurture, nor even particularly to the role of parents in the traditional theories of the child's psychological development. It is in relation to the perceptions of childhood propagated by parents onto their own children, “in how far parents aim to reproduce or transform childhood” (Mayall 2002): 60). This childhood is one that falls within the natural measures of protection and care assumed by all parents and consequently their perceptions of risk in their children's daily lives. It is also one that carries with it parents' own perceptions of the makings of happy childhoods, and their attempts to ensure that these are provided to their children despite the risks and pressures of everyday life. This need not be as idyllic as it sounds – for example, parents who experienced joyous childhoods from their work on the family farm may insist that their children also do the same in their attempts to impart their own ideals of simplicity and fun to their children. The point here is in the effect this has on constructing childhood for the children. “It is through living with parents that young people first learn that they inhabit the status of child. Parental definitions constitute them as children.” (Mayall 2002): 45)

What clearly emerges is the power struggle among children and adults, mainly over the children's days and lives. “Children's own agency in constructing childhoods has to be set in the context of adult power to construct them too – the two kinds of agency are in tension” (Mayall 2002): 162). The adult power referred to here includes not only parents, teachers and other adults the children come into contact with during their everyday lives, but also policies and institutionalised settings that adults design for children.

Notions of power and control are critical to this study of disabled children negotiating their formal and informal space in a residential institution, and will be addressed further later in this chapter.

### III. Childhood as 'Universal' & International Agencies

'There is a compulsive urge to refer to childhood as a unitary phenomenon, its invocation is always meant to describe something shared' (Jenks 2004): 5).

Psychologists such as Piaget, Freud, Erickson and others proposed stage theories for child development. That is, that all children went through a specific order of stages of development throughout their childhood that would eventually lead to their maturing into an adult. These theories have influenced policy and practice with education and special education casting a long shadow. Therefore, although this thesis does not draw on this body of research, it is necessary to summarise it. Developmental psychologists such as those listed above have posited that:

- 'Child development is a universal process.
- Adulthood has normative status.
- Goals of development are universal.
- Deviation from the norm indicates risk for the child.
- Childhood is an extended period of dependence in which children are passive recipients of adult protection, training, wisdom and guidance, rather than contributors to their social environments.'

(Lansdown 2005): 10)

The indelible influence of these theories has been 'the fundamental principle ... that all children throughout the world have the same basic needs, pass through the same developmental stages, (and) react in like manner' to situations (Chatty and Hundt 2005): 6). This became the guiding factor in designing educational programmes and in proposing policy and legislation to protect

children. In all of these, adults assumed the responsibility of determining what was best for the child at any particular age, and presumed that this was optimal for all children everywhere as it responded to universal needs and stages of development. This singular, universal child became the primary subject of international agencies with "child" in their title and its mandate. UNICEF arose in 1948, several years after other similar agencies which focused only on children. These were erected, at huge effort and expense, to address the specific needs of children. They were post-war products of their time, and their social and educational programmes automatically and naturally adopted developmental stage theories at the core of their theoretical framework.

This had further new connotations on the representations and constructions of children as these agencies carried out their programmes across borders, and 'our children' and 'their children' became one. The child was perceived and constructed as having the same needs and the same childhood everywhere. Thus, childhood was universalised, and 'ideal' childhoods were considered the ideal for all children. Within this collective, the "individuality (of children is) dismissed and disregarded", and it is argued that this is a direct result of "our strange obsession with the physical and developmental stage through which ... 'childhood' is most often conceptualised" (James and James 2004): 15).

Such agencies designed programmes and advocated policies for children to respond to what it considered prevalent or in need of intervention. Looking into the statistical data and needs assessment that inform these agencies of the child's needs sheds new light on how the children are represented in these processes. In statistics, children are traditionally lumped under "dependents", confirming their perceived submission to adults' understanding of "their best interests" or "their own good". Analysing the statistical frameworks would also reveal that children only ever appear in terms of (a) the production of children, (b) expenses invested in children, and (c) children's failure to meet the desired requirements (Qvortrup 1990). In general, statistics do

not hold the children as the unit of observation, and consequently neither represent them nor give them a voice.

On the other hand, working with children in terms of “their needs” is a widespread approach that is largely considered to be progressive and enlightened. Besides running the risk of falling in the “universality” syndrome, closer inspection uncovers several disempowering assumptions about children, as indicated by Woodhead (Woodhead 1990):

1. Children are represented as passive receivers of “help” that will satisfy their “needs”.
2. The children bear the brunt of this perceived need and not adults or society. For example, it is the child who needs love and the parents or society who must provide love for him/her. The problem lies in the child.
3. These “needs” are determined by parents, teachers, policy makers, etc. in line with their own thoughts of what is good for the child, and in accordance with their perceptions of a happy and healthy childhood. The child's opinions are not considered in both instances.

A number of parallels can be seen here with the medical model construction of disability described in Chapter 1, thus raising the question of the double burden of oppression that disabled children may experience as a result of their perceived needs both as children and as disabled persons.

Several efforts of this sort are marked with “the common confusion between the natural, biological vulnerabilities and dependencies of childhood, and those which are socially constructed” (Mayall 1996: 58). In safeguarding the almost fairytale ‘time of childhood’, the children are also given delicate and fragile sensibilities and cannot cope with the real world. The child's experience in living with adults in the ‘real world’ is blurred by the generalised representations of children.

It could be thus argued that the interventions and policies for children, that rely on such statistical studies and needs assessments as a guard against personal or social biases, may lose sight of the child altogether as the childhood that they construct does not include the child. They have, it would appear, been provided to serve adult interests and adult representations of the child. We need to question how well this 'ideal' travels as the international agencies seek to "export" happy childhoods, which fall completely in line with their universal social construction of children.

It is precisely when these agencies venture outwards, to where the other children live, that the child's universality crumbles. Issues of culture are taken to be constant and are not woven into programme design or policy implementation. It is apparent that there are different social constructions of childhood in different societies, and that the children, through their contribution to the household chores, or income, or perceived responsibilities, play very different and distinct social roles in their respective communities. This diversity is not represented in the framework of these agencies that are led by globally generalised social assumptions.

### *Children's Rights*

An illustrative example is the UN Convention on the Rights of the Child (CRC), an aspirational document that is meant to include all children and encompass all their rights and needs. The CRC presented a breakthrough in looking at children and their rights through providing a framework that not only protects children but also empowers them, as well as providing a tool with which to effect change at the local level (Boyden 1990). The convention is based on four basic guiding principles: that all children have the inherent right to life and development; that all children have the same rights and must be protected against discrimination; that all children have the right to express their views and to have them taken into consideration; and that 'in all actions concerning children

undertaken by the authorities or other institutions, the best interests of the child shall be the primary consideration' (Hagner 1999).

The CRC was, and continues to be, instrumental as the first international document of its kind to recognise children as individual rights-holders and demand a system that monitored these rights. Their needs, as illustrated earlier, were now coupled with rights and a process of accountability to duty bearers to promote and protect these rights. The CRC consists of rights to freedom, to protection, and needs-based rights or welfare rights – this last group of rights 'are not rooted in the rights to be left alone but in the right to receive certain necessities of life that are defined as being necessary to the particular social status to which those rights are accorded – in this case, childhood' (James and James 2004): 84).

These are clearly basic rights and needs that children should enjoy, the universality of rights not being in question. However, there are different modes of implementation and there are different ways in which they can, and have been, ensured throughout different cultures – thus providing primary insights into the existence of varied childhoods. As such, the weaknesses of implementing the convention at the local level began to show as it was being carried forward for global application. As an essentially global convention, the CRC carried universalised principles of child development, and assumed the capacity at national level to institutionalise social services and policies similar to those in highly developed countries. Not unlike the shift from 'our children' to 'their children' mentioned earlier, where all children suddenly became the responsibility of all adults, the CRC also created grounds for legislative and institutional change that somehow blurred the lines of responsibility further, and authorised the State to interfere in issues concerning the child. Such interventions were also interpreted as a State emphasis on protection more than participation or inclusion (Mayall 2006). Though the natural rights are incontestable in any setting, understanding them and interpreting them within cultural contexts is necessary to their proper and sustainable implementation. The CRC introduced ideals of state or legal intervention where such

systems in many countries were not yet adequately prepared to take on such responsibilities, and where intricate informal structures were more influential on the lives of children. It entitled the state to intervene in the domestic arena, in the private as well as the public domain, and consequently questioned the roles of parents. Whereas this may actually be in the child's interest in the cases of abuse or the like, it interferes with the framework of family that the child is familiar with, and from which he/she traditionally draws a form of security.

This specific issue is highlighted when considering Lebanese children, where the family plays a central role in the life of the child as the basic unit of social structure (Prothro 1967), and the extended family and community play an integral part too. Furthermore, the traits and pride of the individual are frequently considered to stem from his/her family. Thus, interventions that question the character of the parents reflect negatively on the child and on the reaction of the community to him/her. To illustrate, in cases such as those of abuse, the child is certainly considered the victim, and he/she is treated as such, but intervening in a way that creates a sudden break from his/her immediate family carries a stigma that is more acute than being orphaned, in a society and culture where you are identified as the son or daughter of your father or mother; and where even official documents carry the father's name as a person's middle name.

Lebanon can be considered as an illustrative case for the difficulties in implementing the CRC. Since ratifying and signing the convention in 1990 and submitting three country reports, the concluding observations of the UNCRC committee continue to repeat the same concerns. In almost two decades, Lebanon has succeeded in introducing some pieces of legislation to promote the rights of children (specifically Law 422 for protecting children in conflict with the law, and Law 220 for the rights of disabled persons), but continues to struggle with creating mechanisms to support the implementation of these laws, and with addressing more deeply rooted cultural or political issues such as early marriage and the rights of refugee children, respectively, not to

mention a number of rights violations caused by a continuously unstable security and economic situation (OHCHR 2006).

Another intrinsic weakness in a convention such as the CRC is that though its main goal is to ensure equality of treatment and life opportunities for children, the fact that it reiterates basic human rights for a specific group automatically implies their weakness and disadvantaged standing in society, that is '... although Article 4 of the UNCRC defines children as equal to adults in their rights and value, identifying them as a distinct category and seeking to differentiate between their needs and those of adults, the Convention implicitly highlights children's *lack* of equality and power, and the many boundaries between childhood and adulthood that are constantly being reinforced by adults on a daily basis throughout the world' (James and James 2004): 99). Distinguishing childhood as a distinct phase, and separating "the child's and adult's worlds" has been seen by children's liberationists as 'an unwarranted and oppressive discrimination; that this segregation is accompanied and reinforced by a false ideology of 'childishness'; and that children are entitled to all the rights and privileges possessed by adults' (Archard 2004): 71).

Whilst focusing on the constructions and representations of children, two main issues can be seen to emerge. Firstly, the assumption that there is a universal pattern of child development and childhood, which overpowers the local, cultural and social factors that define the children's roles and characters. Secondly, the silent issue of "control" of the child. These agencies, and the development theories, insist on ascertaining what is good for the child, imposing control of children through surveillance and laws, giving control to the state agencies in the public sphere. Examples of these are compulsory immunisation, schooling or state custody of children in cases of abuse.

As a tool addressing the rights of a 'special' group, 'the *raison d'être* of the UNCRC was to articulate those rights that were seen to be universal and central to the process of moving children

from the margins to the centre of society' (James and James 2004): 84). One of the basic principles, that of freedom of expression and participation, strongly asserts the central role of children in their own lives. Whereas this is a welcome move, a quick review of groups of rights will indicate that the mechanism proposed by the convention does not directly speak to significant changes in the status quo of children with the state. For example, 'although the Convention identifies education as a key component of the global childhood and the right of children around the world, it simultaneously, reinforces the role of education policy, education law and educational practices as the hand-servants of the State and the primary means by which different childhoods are produced and imposed upon children in different cultures, in order to produce tomorrow's citizens' (James and James 2004): 85).

For all practical purposes, these State-owned institutions can be considered institutions targeted at children, such as educational institutions. The most common components among these are those of regulation and segregation. 'Within schools children are less creative; less able to construct meaning because their school lives are more or less determined by curricular and behavioural rules and structures' (Wyness 1999): 356; (Wyness 2006). In other words, the system is set up to encourage a commonly held notion of childhood, and children are being moulded into stage-led general constructs of behaviour and roles to ensure that they fully experience 'childhood'. Within this lies a perception of children as in the process of 'becoming', 'children pass through school as they pass through the various developmental stages en route to something grander and more established' (Wyness 1999): 356). Educational reform and global initiatives for children are actually elements that reveal the 'ambiguity' of childhood because they seek to generalize the status of children 'over time, across different contexts and between different children', which poses a quandary when compared to assessing children within focused arenas of the 'home, in school, in the street or in playgroup (where) it is often quite easy to decide whether a specific child is a 'being' or a 'becoming', 'the same as' or 'different from' adults' (Lee 1999): 465-6). Generalising 'childhood' discounts the child's individuality, and in all of these, the child's own agency is

overlooked, and assessments are largely left to those working on these initiatives and in these institutions; namely, adults.

#### **IV. Children's Participation & Agency**

All of these elements bring us to concepts of the participation of children, which essentially seeks to actively include children into all circles of society. Within the articles of the CRC, participation comes through as the right of children to express opinions (Article 12), to gain access to information (Article 13), to freedom of thought (Article 14), and to associate (Article 15). As for participation as a guiding principle, as mentioned earlier, it implies that children should be involved in all decisions concerning them, even if this involvement is limited to informing them of these decisions at the very least. In fact, "four levels of involvement have been identified in the decision-making process: to be informed, to express an informed view, to have that view taken into account, to be the main or joint decision-maker" (Lansdown 2005): 4).

Participation is perceived as a means to ensure democracy, and assert the citizenship of children and young persons (Cairns 2006). Participation is not only safeguarded by the CRC as a basic right, but also as a means for ensuring that interventions and policies are appropriate for children, and are simultaneously protective and respectful. Children's participation, in effect, brings forth the children's perspective and standpoint on their daily lives and surrounding environment. Such tools and mechanisms would thus need to be sensitive and responsive to all children, taking into consideration any possible obstacles – whether social or personal – that may prevent any child from participating. By doing so, concepts of universal childhoods and their subsequent policies and programmes are challenged, and systems are guided into responding to and respecting the evolving capacities of children. This not only recognises that childhood is socially constructed by these blanket theories and traditional practice, but it also provides some preliminary guidelines

with which to incorporate “the complex realities of children’s acquisition of competencies” (Lansdown 2005): 13).

At the heart of this is the subtle assertion that children are active agents of social change, that they carry an agency of which they have been dispossessed in predominant constructions of children. Although commerce has long viewed children as consumers, and education is slowly learning to view them as interpreters of the world around them, culminating that into the role of an actor presents a number of contradictions to perceptions of childhood (Smith 2000). It not only challenges perceptions of children, but also blatantly puts the role of adults into question. It is, thus, not surprising that the general resistance to the participation of children has stemmed from adults, whose fears of participation have reflected traditional notions of children’s (in)capacities, of the established roles of adults for knowing what is in the children’s best interests, but more intricately, their fear that the participation of children eliminates their roles altogether (Damaj 2007). Similar reactions have emerged to concepts of children as citizens where the common perception is that “it is the rights-bearing adult individual who is endowed with citizenship” (Roche 1999): 483).

This struggle illuminates the power of adults in relation to the roles of children, and the difficulties that have been faced in bringing forth new constructs of children and childhood. Steps towards facilitating this shift have been presented in continued research and resources that seek to simplify concepts such as participation, citizenship, rights-holders and individual childhoods. One such piece of recent work has explored the concept of evolving capacities, where three conceptual frameworks have been proposed:

- a. ‘Firstly, as a **developmental** concept, recognizing the extent to which children’s development, competence and emerging personal autonomy are promoted through the realisation of the Convention rights. In this sense it imposes obligations on States parties to *fulfil* these rights.

- Secondly, as a **participatory or emancipatory** concept, denoting children's right to respect for their capacities and for the shifting of responsibility for the exercise of rights from adults to children in accordance with their levels of competence. It imposes obligations on States parties to *respect* these rights.
- Thirdly, as a **protective** concept, which acknowledges that because, throughout childhood, children's capacities are still evolving, they have rights to protection on the part of both parents and the State from exposure to activities likely to cause them harm. It imposes obligations on States parties to *protect* these rights.'

(Lansdown 2005): 15).

Other studies on the resilience of children in situations of conflict and disasters have indicated that children adapt to crises in a more flexible manner than adults, and have through their own agency been "able to have considerable positive impact on the psychological and emotional worlds of adults" (Boyden 2003):10) by actively restoring their traditional adult roles, thus attempting to restore the adults' worlds to a sense of normalcy.

Such studies contribute to the learning process being undertaken globally in understanding children as active social agents, as participants and rights-holders, and in working towards measures that respect their individuality, their capacities and their rights.

### **C. Power & Control**

Within the literature on the sociology of childhood, and the research that frames children as social agents and a social group, an issue that consistently arises is that of power and control, between children and adults, and their proposed institutionalised systems for children.

In addressing the nature of this relationship, one cannot help but reflect on the work of both Foucault (1973, 1991) and Goffman (1961, 1963). As Hacking has written "Foucault proposed various ideas of a structure that determines discourse and action from the top down. Goffman

gave us the local incidents and idiosyncrasies that lead us from the bottom up” (Hacking 2004): 288). The focus in this thesis on an institutional setting for children with visual impairment, the children are viewed both by professionals and the wider society as vulnerable beings to be controlled and trained, so the analysis of disabled children will draw on Foucault's ideas on control, surveillance, power and resistance in his seminal work 'The Birth of the Clinic' (1973), and Goffman's studies of total institutions and stigma (1961). There are parallel and different forms of social oppression through policy and practice that relate to both disability, being children, and total institutions that shape these children's experiences. This will emerge as particularly relevant when investigating pathways for children's participation in a residential institution for the blind, and the informal pathways of resistance created by children within that controlled setting.

Foucault defines power as resulting from the relations created by formal and informal systems. He did not see it as “force nor capacity nor domination nor authority” but rather “a complex set of relations” that “enables or enhances some actions and inhibits or precludes others” (Prado 2000): 68-69).

Institutionalisation figures heavily in education and in rehabilitative services, for children and disabled persons respectively, as a way to train and shape children and disabled persons into mature, 'normal' actors who can, upon successfully meeting the standards raised by these institutional settings, take part in society. Power is exercised through measures of control and surveillance often delivered in institutional settings. The organisation of time and space within these institutions is carefully designed “to ensure the increasingly efficient surveillance of individual conduct and the exercise of what Foucault calls normalizing judgement” (Driver 1994): 119). Children and disabled persons are seen as 'anomalous' beings who would benefit from these measures to become 'normal' and acceptable. “Those who could not participate in this new social realm could only be seen to be lacking the symbolic and disciplinary qualities of the autonomous, rational, market-driven liberal subject and thus were defined as aberrant” (Galvin 2006): 501).

Foucault's 'The Birth of the Clinic' (1973) was a lucid analysis of how the medical profession, through the development of the clinic, hospital and an organised profession with 'a clinical gaze', exercises power; "... the gaze implies an open field, and its essential activity is of the successive order of organisations..." (Foucault 1973):121). This "disciplinary power was ... a colonizing form of power; it cultivated ... ways of seeing, calculating and ordering" (Driver 1994): 127).

Foucault argues that "conceptions of freedom and human agency are produced in relation to a particular conception of power" (McGowen 1994): 97). Therefore, initiatives of minority or oppressed groups that seek to challenge and change the overriding order by using its same tools may end up only supporting it further, and not, essentially, changing the reality of the group's discrimination and oppression. As Foucault argues that this power is not possessed but exercised (McGowen 1994), 1994) it follows that altering the reality perpetuated by this power lies in altering the exercise of this power in its various forms. State services and programmes are one aspect in this process, as is the community, family and individual. As Foucault stated: 'How can the growth of capabilities be disconnected from the intensification of power relations?' (Foucault 1991): 48).

In Goffman's study of a mental institution, he described 'total institutions' as "a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (Goffman 1961): xiii). He asserted that institutions are permeated with actions that erase identities, which are then re-defined by interactions between institution staff and residents (Malacrida 2005). This symbolic interaction with those in control, with peers and with the actual setting, influence self-perceptions and self-presentation such that we present ourselves "in accordance with our own places in the status hierarchy" (Lemert and Branaman 1997): lxiii). It is these interactions that associate stigma with perceived deviance in our bodies, and it is through these relations that we learn to manage this stigma and normalise our actions in order to obtain 'phantom acceptance' (Lemert and Branaman 1997): 76), as explained in Chapter 1.

The analysis of both policy and practice in this thesis will be informed by Foucault's theory on power. In addition, the work of Goffman in relation to social and symbolic interactions will be utilised, drawing in particular on his work on stigma (Goffman 1963) and total institutions (Goffman 1961). Whereas Foucault and Goffman have both been referred to in studies on disability issues, they have rarely been drawn into studies of childhood. However, this is not a Foucauldian analysis nor is symbolic interactionism foregrounded – their work is drawn upon for understanding power and control. This research study uses the framework of the sociology of childhood and the reconceptualised social model of disability to analyse considerations for disabled children's participation and agency within the systems of power and control that they experience through policy and in their lives as residents of an institution.

## **D. Conclusion**

This chapter has reviewed recent work on the sociology of childhood, and its redefinition of children as social agents and an oppressed social group, and the obstacles that its assertions come up against in light of a broad heritage of social practice, language and development stage theories that construct the child and childhood differently. This chapter has also illustrated how these representations have impinged on the construction of childhood in society and the development of policy.

The shortcomings of generalised constructions of childhood clearly emerge when contrasted with elements of rights, individuality and autonomy, and when compared to an expanding understanding of children as a diverse minority social group, and childhood as a culture. Furthermore, children can be better understood within their social context – in their relations with other generations, in their responses to social parameters, and in the active roles that they find for

themselves as social agents of change. Similarly, programmes and policies and their respect and understanding of the culture of childhood and the individuality of children can be gauged according to measures that they have taken to ensure the meaningful participation of children; one that responds to the child's evolving capacities, and addresses any discriminatory obstacles preventing his/her participation.

It has also been illustrated how these constructions have determined the social role of children and also influenced their identities. The effects of legal and institutional practices have all been shown to influence the processes by which children 'make meaning' of the world around them and determine their place within these social worlds. This directly impinges on how they negotiate their own identities within these social surroundings.

"However one makes sense one's sexed body or the colour of one's skin, our identities have to incorporate, negotiate and/or contest representations of gender and skin-colour. The gaze of the other makes these identities unavoidable. In some senses, therefore, identities are imposed onto us... identities are always constructed through and against representations" (Howarth 2002):158-9).

The literature reviewed in Chapter 1 and 2 demonstrates that the dominant social constructions of children and of disabled persons have been as homogenous groups, and that they are not perceived as able and prepared to participate fully in society. Aside from excluding them socially, this has also sidelined them from participating in decisions pertaining to their own lives.

The disability rights movement and the social model of disability were spearheaded by disability activists, perhaps it can be argued that children could equally bring about such a change to their own issues should they be allotted the space and respect in which to express their opinions and participate. In research with disabled children, the methodology and framework will need to

recognise and address the doubly-compounded discrimination and oppression that they face as children and as disabled persons.

This thesis will be adopting a rights based participatory and contextual approach influenced by the work of sociologists of education and disability and anthropologists of and for childhood in this case study of visually impaired children in Lebanon. This approach is considered the most relevant in this investigation of the inclusionary versus exclusionary nature of policy and practice; the availability of mechanisms allowing for children's participation in these contexts; and the impact of these practices on the self-identities of disabled children. The perspective taken here is influenced by the work of Oliver, Barnes, Shakespeare, James, Mayall, Boyden, Lansdown, Jenks and others who place an emphasis on the importance of context and culture and the importance of a child centred approach, and who have indicated the direct impact of social, cultural and institutional practices on children's identities.

## **CHAPTER 3 – RESEARCH METHODS**

### **A. Rationale & Aims of the Research**

This research sets out to investigate the following research questions:

1. To what extent do current policies and practices in Lebanon foster inclusion versus exclusion of disabled children under 12 as part of a rights based approach?
2. What are the mechanisms and processes that allow the voices of severely visually impaired children in residential institutions to be heard?
3. How do elements of inclusive and exclusive practices impact on the social identities of severely visually impaired children in Lebanon?

These questions were addressed by:

- a) Conducting desk research on the policy and social services environment in Lebanon.
- b) Eliciting the voices of visually impaired children and their views on their lives and their roles in their households, schools and communities.
- c) Eliciting the views of their families, and professional carers on their perceptions of the visually impaired child's capacities and social roles.

### **B. Research Methodology**

**Quantitative methods** derived from a positivist approach have failed to properly represent the children and disabled persons or address their needs. Qvortrup (1990) illustrated that statistical data has not generally held children as the unit of observation, and lists them mostly as 'dependants', or expenses, or 'family size'. As for disabled persons, Oliver (1987) would argue that these 'headcount' methods should be dropped mainly because 'at the level of epistemology, if disability is really socially caused, then research should aim to identify these social causes with a

view to eradication rather than further contributing to the individualisation of disability' (Oliver 1987): 11). These methods can be considered alienating to the disabled study subject whose own daily-life experiences of the disability are not foregrounded thus producing outcomes that further confirm the social constructions of disability as perceived by non-disabled researchers.

The preconceived perceptions of the researchers have equally affected **qualitative research designs**. These research projects have been greatly influenced by the dominant **social constructions** of childhood and of disability (Alderson 1996):107), which were described in previous chapters. Thus research with children has fallen mainly within adult interests of long-term factors affecting their growth into becoming adults. The research design has thus 'regarded children as the object of the enterprise to be studied ... research has been on children, not with them or for them' (Hood, Kelley et al. 1996):118). Alternatively, designing research that is 'for children and that aims to make children heard would require 'listening attentively to their agendas, and participating with them in the research process' (Hood, Kelley et al. 1996):119). The researcher would need to respect children's rights to be 'informed and listened to in all matters affecting them' (Alderson 1996:115; UN, 1989).

Likewise, designing research that attempts to understand the experience of disability requires that the disabled person be involved in the research process (Oliver 1987). Such an active involvement would involve deeper self-reflection on the part of the disabled person, and would allow the researcher to better understand the study subject. The research process would hence be transformed from one that is alienating and often oppressive, to one that is emancipatory and relevant to the study subjects (Oliver 1996). Ethnography, as a method for this type of research, is supported by James and Prout who argue that it 'allows children a more direct voice and participation in the production of sociological data than is usually possible through experimental or survey styles of research' (James and Prout 1990): 8).

Additionally, actively involving the main study subjects (children or disabled persons) as primary informants may also enhance the **validity** of the research. For example, in their research with children, Mahon et al (1996) have found that it is 'neither theoretically nor methodologically appropriate to rely on proxies to represent the views and experiences of children' (Mahon 1996:146). The individuality of children and the diversity of family situations implies that 'valid accounts of children's attitudes and experiences (can) ... only be obtained by engaging directly with the children (and by) treating them as independent actors who (are) engaged in negotiating a complex set of relationships and loyalties' (Mahon 1996):148). Participatory research with children has provided insights into the lives of children and communities that was inaccessible through traditional research methods, and has gained a rapidly developing body of resources outlining tools and methods to ensure the meaningful participation of children in research. (Johnson, Hill et al. 1994); (van Beers 2002); (Laws and Mann 2004); (Lewis 2000); (Boyden and Ennew 1997; Save the Children 2003)

The main subjects of this study are children, and child-focused research raises several **ethical issues**. At the forefront is the concern for infringing on the boundaries that define family, home or school. It would almost be impossible for a researcher to enter these contexts without causing some disruption to the status quo. This naturally needs to be handled as sympathetically and delicately as possible, but 'the very process of crossing these boundaries, and the interactions involved in so doing constitute data – the process tells us something of people's ideas about the family and the home' (Hood, Kelley et al. 1996):119), as it would inform us of the perceived roles of disabled children.

Ethical issues are relevant to research with children. The aims of the research need to be made as clear as possible to the children to address concerns about obtaining proper consent from the children for taking part in the research. There is a need to avoid raising expectations among the

children that the research, or their involvement in it, would be succeeded by any type of change in their situation. (Mahon 1996)

The role of the researcher and his/her knowledge of the children's voiced concerns may also raise ethical questions. Depending on the gravity of these concerns, the researcher may find him/herself compelled to take active steps towards protecting a child from a risky situation. Such incidents cannot be accounted for in the sample selection or the research design, and the researcher's interference is usually supported by laws and regulations for child protection (Mahon 1996). However, the line that justifies such interference or condemns it is not always clear, and confidentiality issues place the burden of such a decision upon the researcher's discretion.

This ethnographic study was conducted by a Lebanese within her own society, and therefore insider-outsider status was a constant issue during fieldwork. As a sighted adult woman, I was not an 'insider' in a school for visually impaired children. However, I was part of the host society. Insider-outsider status presents both advantages and challenges to the research process. 'Insider' status leads to an 'intimate knowledge (that) offers insights that are difficult or impossible to access by an outsider' (Labaree 2002): 100), but may equally bias the researcher's data and analysis. As an 'insider', the researcher is 'pushed to acknowledge and explore (one's) "positionality" throughout the research process' (Colic-Peisker 2004): 91). Though a challenge, this process of reflexivity and of contextualising oneself within the study environment and population becomes a part of the data and enriches the analysis. The data itself becomes more accessible, not only through an automatic understanding of dialects, nuances and the deliberate use of idioms and proverbs, but also in being reared in acceptable, and thus non-threatening, social behaviour that facilitates relatively smooth interview processes. This can also be supported by the researcher's gender. In Lebanese society, as in many others, women are not perceived as intimidating, and 'a woman's power is never as serious, as threatening, and as distancing as a man's' (Colic-Peisker 2004): 88). Methodologically, there is added motivation for employing

ethnographic approaches in working with people who traditionally rely on oral narratives to transmit culture, as the Arabs and visually impaired persons, where this culture 'is most easily accessible by an insider of that group' (Labaree 2002):106). This is also pertinent to research with young children, where children can only assent to participating rather than providing informed consent, and genuine assent can be obtained over time by nurturing trust and comfort in the research process (McGinn 2005). This alone, however, does not turn the researcher into an insider. The researcher needs to create a role for him/herself within the research setting which children can recognise and relate to. It is argued that the 'insider-outsider' position lies on a continuum, where 'the boundaries of insiderness are situational and defined by the perceptions of those being researched' (Labaree 2002: 101).

This was very apparent in practice as my presence in the institution gradually changed from being a visitor to a trusted and known adult to both staff and children. Though I had become more of an insider, I was still anomalous for both as I was not an employee or resident at the institution.

Additionally, during the period of my fieldwork, I was working in programmes for children's rights and disability where my work focused on developing inclusive approaches. This posed a challenge in terms of having empathy for the institution I was researching which held contrasting values. This was gradually facilitated with time as I became better acquainted with the staff and students, and began to recognise the opportunities that the school offered. It was also facilitated through discussions with the staff, who were aware of my work, and who considered their work at the institution as laying the groundwork for inclusion. Such discussions helped to neutralize our seemingly opposite positions and contributed to uninhibited and frank exchanges, which greatly enriched the data collection.

## C. Research Setting

The following institution, centre and school settings were where I gathered data on how work with visually impaired children in Lebanon is carried out. They are described here in order to provide a glimpse into the workings of such programmes in Lebanon, and as three different forms of services being offered to visually impaired children. The main case study site for this research was the institution, where ethnographic fieldwork was undertaken in addition to group and individual interviews. It is also the only setting where services are subsidized by the government. More limited participant observation and interviews were conducted in the other two settings.

### 1. Institution – *The BAL School for the Blind*<sup>1</sup>

This school was established in 1957 through the work of the Lebanese Society for the Blind, which was co-founded by the country's First Lady at the time. The school came into being with donations from the government and individual donors, and still greatly depends on government subsidies and donations as a main form of income.

Its enrolment has increased from around 20 students in the 1960's to a current student body size that exceeds 100. The curriculum spans pre-school to baccalaureate level, and goes on to offer assistance in college entrance exams, or vocational training. It also provides an avenue to integrate some students into mainstream public or private schools at the secondary level, whereby the students are given additional coaching, teaching aids and tutoring by the school's staff. The school operates mainly as a boarding school, and is attached to its sister school, a school for the deaf, on the same campus.

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<sup>1</sup> The name of the school and other settings have been changed in this thesis

## 2. Integrative programme – *GK Pre-school*

The GK Pre-school was founded in 1974, and it was established as a development NGO working with children in the Palestinian refugee camps in Lebanon. One of its centres operates out of a refugee camp in Beirut where a nursery, day-care centre and Kindergarten Resource and Training Centre are set up. This is one of the GK centres that contains a programme for sensory and mentally disabled children, of whom there are 34 both in the Beirut and Saida centres. Where the visually impaired children are concerned, the programme has set up a parallel classroom for the children, with some lessons taken together with their non-disabled peers. The driving force behind some of their class design has been one of their exceptional primary school teachers, who is herself severely visually impaired. As a pre-school service – a facility that is not offered through the Ministry of Education or UNRWA – students at GK Pre-school are prepared for entry into 1<sup>st</sup> grade in regular schools. In the last few years, the centres have succeeded in having their visually impaired children admitted into regular UNRWA schools and integrated into the school system with little to no additional help.

## 3. Inclusive school – *ABS School / Beirut*

The Youth Association for the Blind (YAB) has been working with mainstream schools towards the inclusion of visually impaired children since 1993. They have worked with approximately thirty schools nationwide, and whereas they have always had a positive influence in empowering the visually impaired student for full inclusion, the same is not true for continuing the programme at the school after the student has graduated.

One school that is currently cooperating with YAB and has been doing so for several years is the ABS school in Beirut, which has had one child admitted and included in its system at the elementary level, and two others have followed since. The school has made minor extra

provisions for the child, but the parents, YAB workers and teachers have worked together closely to ensure the child's total integration in the school system, and in handling other aspects of his daily life. This has included converting his text books into Braille, providing a Braille typing machine, and training the child to work with the machine. Support educators work with the teachers to adjust and adapt their teaching methods in ways that will communicate the desired concept to be learned to the child, as well as creating teaching aids from props readily available in any school setting. The child's presence in the classroom has also given rise to several activities and games with his classmates, who experiment with a blindfold to find out how their visually impaired friend manages to excel in his classes, move around the school, and recognise them all with such little trouble.

## **D. Study Population**

### **i) Children in institutional settings**

The study focuses on moderately and severely visually impaired<sup>2</sup> children, aged 7 – 12 years, who attend the BAL School for the Blind in a suburb of Beirut.

This age group was chosen to ensure that the children would be old enough to be sent to some form of schooling (considering the five-year mandatory elementary schooling law in Lebanon), and young enough to still be in school.

The BAL School for the Blind was chosen as the main research site as it was the only such non-religious institute that was fully sponsored by the government. As such, it did not have any religious or political affiliations, was financially supported by the government and private funders, and was assigned as the referral centre for blind children by the Ministry of Social Affairs and

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<sup>2</sup> Severe visual impairment' is meant to refer to visual impairments that are not correctable through simple aids

UNRWA, thus providing services for Lebanese and Palestinian children alike. As such, it was the only institute in Lebanon with a student body that was representative of the diverse religious, ethnic, and socio-economic groups of the population in the country. Furthermore, as it was considered a part of the public sector, it would be directly affected by changes in government policy.

In addition to the organisation ethnography, I gathered data from some inclusive settings through participant observation sessions in an integrative pre-school (GK Pre-school), by interviewing parents of children who had been included in regular schooling (ABS School) and by interviewing members of three stakeholder organisations (disabled people's organisations and parents' organisations) that support inclusion of children with visual impairment or other disabilities in regular schools.

**ii) Paid and Unpaid Carers & Alumni:**

Ethnographic fieldwork was conducted in the BAL school with students and teachers, and home visits were undertaken to elicit the views of family members. In addition some alumni were interviewed to provide a retrospective personal perspective of attending and living at BAL School. Data was gathered from members of this group through participant observation with fieldnotes being recorded, in addition to natural group interviews and in-depth individual interviews.

## **E. Research Methods**

Before starting with the research process, and to ensure that the methods and objectives of the research were ethically appropriate, a synopsis of the research was presented to the Lebanese Union of the Blind to obtain their approval. This was also submitted to the research ethics committee at the London School of Hygiene & Tropical Medicine in relation to this PhD research.

### **Secondary Data on Policies & Service Provision**

The secondary data consisted of a desk study **reviewing current policies** addressing the issues of disabled people, and a mapping of the services that were available for children with visual impairment.

Governmental and UN agencies that had worked on policies and legislation were more than willing to provide data that they had published in this regard. The confusion, however, arose when trying to draw common threads between different studies which had grossly varied estimations of the number of disabled persons in Lebanon and the type of services provided by public service centres and institutions subsidised by the government. Additionally, it was not possible to obtain drafts of the executive plans or decrees that would translate the current legislation into mechanisms for practical implementation. These were exclusively being developed by a non-governmental organisation that had been given this task by the Ministry of Social Affairs.

**Table 3.1 Chart of Data Collected**

	Participant Observation (sessions)	Natural group interviews	Group Work (sessions)	In-depth interviews	No. of Informants
Children	97 (Jan – Mar 01 & Oct 01 – Jun 02)	4	48	13	30
Teachers & School staff		1		4	10
Families		1		5	13
Alumni				5	5
Stakeholders		2			6
Experts (leading ophthalmologist)				1	1
<b>TOTAL</b>	<b>97</b>	<b>8</b>	<b>48</b>	<b>28</b>	<b>65</b>

## Primary Data

### 1. *Participant observation in institutional settings:*

I undertook 97 sessions (half days) of participant observation between January 2001 to June 2002. Analyses of participant observation as an approach have raised questions as to whether 'the process of participation in participant observation should be taken as a question within the overall theme of interpretation in general ... the culture as text, the researcher as reader – or whether ... the approach should be a social psychological one: the participant observer is a member, of a sort, in the group that is being investigated, trying to live its life...' (Ashworth 1995): 371).

Though I did not become a member of the group of children at the heart of the study, I sought out a perceived natural role within the context of their environment as boarders at the school, and became a member of that larger group. This, at first, took on the form of attending several classes with the children. They were accustomed to outsiders, as the school took in several

university students (majoring in education, communication, journalism, etc.) as interns each year. I attended classes and assisted in supervising the children during their playtime in the courtyard. This period allowed me to become better acquainted with the children and to develop a degree of mutual trust. It also provided some insight into identifying the type of group work that I could later take on with the children.

A more cursory form of participant observation was also conducted at the GK pre-school, which included children with visual impairment in regular classrooms. I spent seven days at the pre-school over two weeks, during which I shadowed severely visually impaired children in their activities as well as conducting informal interviews with the director and a small sample of the staff.

Ethnographic field notes were taken throughout the process of data collection. This type of journal is intended to document my observations during the fieldwork and provides a data set in itself. Such notes were also used to account for my views during the data collection that would in turn account for any possible research bias. These and all other field notes were handwritten in short form either on-site or immediately after leaving the research field site. They were immediately transcribed from Arabic to English and were later typed in Word, listed chronologically, numbered and dated. These notes frequently contained references to observed conversations and quotes from the children and staff.

The first stages of the participant observation at the BAL School were both smooth and frustrating. Ironically, attending classes with severely visually impaired children and, occasionally, visually impaired teachers, made the process of blending into the background and quietly taking notes an unobtrusive process. Moreover, the school staff and the students were, for the most part, unsuspecting of the presence of an observer and were generally

helpful. Although the staff could not always understand why I was so interested in the children and not in talking exclusively to them.

I had entered into the school with my own ideals of active learning, participatory methods in education, and inclusion. During the first few weeks at the school, I was constantly torn between my lack of sympathy for the traditional, disciplinary school management and teaching methods employed in the school, and my desire not to influence the setting that I had come to study. Ethical issues continued to arise; though I had only gained access to the institution after presenting a synopsis of my research to the management, outlining my objectives and proposed methods, I did not feel when I started my data collection that the management and teaching staff had grasped the aim of my research, and I found myself hesitating to move on to the next phase of research, before I felt that they had understood and approved the reasons for my presence. This was also necessary in order to acquire respect for the privacy of my future interviews with the children, and ensure that neither the children, nor I, would be urged to disclose what was said. Though curious staff would occasionally ask me what was said in an interview, they did not pry if I hesitated to share details.

These factors made it difficult initially to be enthusiastic about visiting frequently to carry out participant observation. Especially after witnessing an incident of corporal punishment exercised against a young student, and not being able to intervene in any way as a neutral participant observer. However, through getting to know the children and some of the staff, recognising some of the ways that they had found to adapt to their setting, and realising some of the opportunities that the school had indeed provided, changed that. My presence at the school became progressively familiar to all concerned, which greatly facilitated the participant observation and the following phases of research.

Additionally, during the period of this data collection, I had taken on consultancies with NGOs to develop strategies for their disability programmes. This greatly enriched the data collection process as it allowed for timely and immediate opportunities to process my observations within the broader societal context, and in light of disability organisations' initiatives in the broader society and with government. The situation was similar to that described by Shuttleworth in that 'my multirelational engagement with the disability community kept relevant issues continually in my awareness...' (Shuttleworth 2004): 50).

**2. *Natural group interviews:*** with groups of disabled children, professional staff and stakeholders

These were intended as natural group interviews conducted with children attending the same programme, and staff working in the same setting. Professional staff consisted of teachers, programme organisers and directors, as well as support staff (housing, administrative or janitorial staff) who had regular contact with the children. 'Stakeholders' refers to disabled persons and parents of disabled children who had taken on an active role in lobbying for the rights of disabled children and adults.

Such group interviews are considered more conducive to disclosing information and exchanging views and opinions. The presence of peers allows for the interview to become more conversational, thus more natural within that group, and focuses the attention on the topic and not the persons expressing their opinions (Graue and Walsh, 1998). They were also found to be useful for testing group opinions on issues and assumptions that emerged in other phases of the research, such as during the ongoing participant observation, or in-depth interviews. Unfortunately, they can also be dominated by a few in the group, preventing others from expressing their opinions. This dynamic in itself is an important piece of data, especially

in a study that is attempting to identify channels that allow children to express themselves (Rubin and Rubin 1995).

The natural group discussions that took place with the children occurred mainly during the group work sessions with the researcher (see paragraph below). Additionally, a brief and informal group interview with parents was attached to a meeting of the Parent's Committee.

The main group interview was held with the professional staff at the school. Though informal group discussions had taken place with the staff during their coffee breaks, a group interview was arranged with the teachers, where almost three quarters of the teaching staff participated.

The stakeholders' group interview was conducted with representatives of disabled peoples' organisations and parents' organisations to discuss their views of disability politics, policies and provisions in Lebanon and the role that they play in it. These were two disabled people's organisations (Youth Association of the Blind, the Lebanese Physical Handicapped Union) and one parents' organisation (Lebanese Down Syndrome Association) who had been actively involved in lobbying for disability rights, as grass roots organisations addressing the education and social life of disabled children.

### **3. *Group work with the children***

Conducting group work with children presented the opportunities for employing creative and active methods of drama and expression. In terms of data collection, working with the children provided a different perspective into the children's lives and views than those obtained in the group or individual interviews. The group work was adopted as a mode of eliciting the views of

the children about the world outside the school in a fun setting, as well as providing a glimpse into the dynamics of interaction between the children and the staff.

Due to the time restrictions of the children's schedule, I was allocated time in the afternoon with the children who are boarders. The administration asked for the session to be educational, and upon consulting the children, it was decided that the session would involve story telling in English. This quickly floundered as the children had little wish to pursue additional "studying" in their free time, and the session became a time for artwork. Play-dough, colouring pens (for children with low-vision) and other tactile material were brought in for a daily one and a half hour session of art exploration. The children were broken up into two groups of 7, each group came in every other day, and the material was left in their care.

This was the type of volunteer work that was accepted by the administration, and thus allowed for regular access to the children, even during weekends and other non-assigned times. It also provided a channel for communicating with, observing and interviewing resident staff.

4. *In depth interviews* – with the children, a sub-sample of teachers, alumni, as well as parents, siblings and other family members.

*The sample:*

- Of the student population at BAL School, 18 children were among the 7 – 12 years age group. Fifteen of these children were boarders at the school and were chosen as the study sample for this research. Fourteen children took part in the group work conducted by the researcher, and it was only possible to conduct in-depth interviews with 13 of them.

- Out of these 13 children, a sub-sample of 4 children was identified for further in-depth study in the form of home visits and in-depth interviews with the parents, siblings and other family members. Field notes of the home visit also formed part of the data.
- The criteria for selecting this sub-sample ensured a diverse representation of the children in these settings in terms of gender, age, socio-economic status and religious background, as well as degree of visual impairment. The interviews were aimed at eliciting in-depth information about the perspectives of the respondents.
- This helped draw out the views of the children and their families regarding their children's disability and their daily lives, as well as the extent of their perceived and actual involvement in decisions concerning them.

### ***The interviews***

#### ***With the children:***

The interviews were semi-structured and the interview guide for children (Appendix 1) contained topics related to what they liked most and least at home and school, how they dealt with issues, the support system that they perceived, their relationship to the school setting, to their community, and their future aspirations.

The interviews took place after I had been at the institution for some time, and the children had become quite familiar with me. However, as this was the first time that I was addressing them directly, I wanted to make sure that they were clear on what I was doing. I explained to them, as a group, that I wanted to interview them, and why, and set out a schedule or order in which to meet with them. Depending on their age, shyness and preference, some of the interviews were conducted with the children in pairs. This greatly depended on the children's preference about expressing their thoughts with a friend present or not.

- ***With parents:***

The interview guide for meetings with parents and families (Appendix 1) mainly dealt with the discovery of the impairment, the services used, how they were referred to the institution and their relationship with the decision-making processes there, the role that their child played in the family and their hopes for the child's future. These interviews took place during home visits, mainly with parents. Both mothers and fathers took part in these interviews, as well as grandparents and siblings who were available and interested in participating.

In addition to parents of children at BAL School, one in-depth interview was conducted with the mother of a severely visually impaired 9-year-old child who had been included in regular schooling from the beginning.

- ***With teachers:***

In addition to the focus group with teachers, two teachers who lived at the school were also interviewed. These were unstructured interviews that built on events that had taken place that day, or on issues that I had observed and asked them about.

- ***With Alumni***

Alumni interviews were sought to provide retrospective accounts of their time in the institutions, and the period that followed. These were semi-structured interviews and were guided along similar issues as those contained in the children's interview guide.

All of these interviews were conducted in Arabic, and, with the exception of the group interview with professionals and staff, a tape recorder was not used. Thus, I was writing down responses

throughout the interviews, and supplementing them with other notes or observations immediately afterwards. The notes were taken in both Arabic and English before being fully transcribed into English. In transcribing into English, great care was taken to ensure that the intended nuance or meaning was safeguarded. There was a slight advantage to taking notes in both languages during the interviews, as this allowed me to double check with the interviewee what they meant to say, and carrying that into the data sets to be analysed.

## **F. Data Analysis & Emerging Themes**

The data was analysed for themes inductively. The inductive approach took place during the entire process of the data collection, where themes were teased out as per the issues raised in the literature review, and as provided by the study subjects during the fieldwork. This falls in line with the *Grounded Theory* method of research adopted in this study, where theory is uncovered through the systematic analysis of data, where data includes other existing theories, one's own and other's insights, and empirical evidence (Graue and Walsh 1998).

Initially, the researcher developed lower order descriptive categories using a content analysis approach. Four higher order themes were then developed, as were sub codes within these themes. The four themes were: (a) Control and resistance versus freedom/ participation, (b) Social links – belonging versus “out of place”, (c) Social links – social support, family, friendship, (d) Identity – aspirations and self-determination. The data was coded, categorised and sorted along these codes with computer assistance.

The process of memoing that accompanied the coding shed light on the main themes that emerged from the data and separated the analytical reflections from the data. This led to other

rounds of coding as new connections were recognised. Furthermore, questions concerning some of these themes were introduced into alumni and stakeholder interviews that were being conducted after the analysis had started.

Notions of belonging and attachment, to a group or a place, were present in all interviews with children, parents, teachers and alumni. This, in turn, brought out issues of identity and socialisation as directly or indirectly expressed by the children and others. Similarly, by investigating modalities of control and participation, hierarchies of formal authority and informal power emerged from the data, which led to other rounds of coding.

## **G. Conclusion**

This is a qualitative research study in which an organisational ethnography was undertaken within one institutional setting with additional limited participant observation and interviews in two other educational settings and some homes of children. The participant observation involved taking the role of a visiting volunteer teaching assistant/helper within the institution for some months. A number of individual and group interviews were completed with teachers, children, alumni and family members. The material was analysed through content analysis with lower order and higher order categories. These methods were chosen as the most effective way to elicit the voices of these children, their teachers and family members. Additionally, policy materials were drawn upon to place these experiences and practices within the current policy setting in Lebanon.

## **CHAPTER 4 – LEBANESE POLICY CONTEXT • PAST & PRESENT**

### **Introduction**

The analysis in this chapter addresses research question 1 which seeks to investigate to what extent current policies and practices in Lebanon foster inclusion versus exclusion of disabled children under 12 as part of a rights based approach. The argument presented in this chapter is that the current new Law 220 is influenced by a rights based approach, which can promote inclusion, but is not being implemented owing to a society that has a predominantly charitable approach to disabled people that supports exclusionary practices.

This chapter is laid out in two main sections. Part I explores the historical backdrop of the political set up in Lebanon's current system of government, and hence its mechanisms for legislation, policy and state social services. The influences of the colonial past, multi-confessionalism and the geographic distribution of the population are described in relation to how this potentially impacts on the status of children and disabled persons within policy. It presents examples of some cultural practices and existing services for children and disabled persons.

Part II is an analysis of the path towards existing policies concerning disabled persons and investigates the policy and legislative context that has eventually led to Law 220 'Rights & Access for Disabled Persons' in 2000, which was lauded as the most progressive in the region. Closer analysis of the law, however, by comparing it to the principles of the medical and social models of disability outlined in the literature, reveals the chasm between the law's rhetoric and its effective implementation, mostly as a result of the unchanged governmental and societal systems. It also underlines the marginalisation of children in measures that remain heavily adult-focused.

## Part I – Background

### A. Historical & Political Context

Lebanon lies on the eastern coast of the Mediterranean Sea. It is a small country of 10,452 sq. km (4,036 sq. miles) that is bounded by Syria on the North and East, and by Israel on the South. Owing to the sensitivity of the religious and ethnic affiliations of the population, there has not been a census in



Figure 4.1: Map of Lebanon (Source: CIA World Fact Book 2006)

Lebanon since 1932, but the estimated figure provided by the CIA world fact book for July 2006 is 3,874,050. This figure only includes Lebanese citizens, and does not account for the large number of Palestinian refugees and mainly Syrian foreign workers living in Lebanon. (CIA 2006)

The land that lay at the heart of Phoenicia more than 7,000 years ago emerged as a republic in 1943, after enduring centuries of Ottoman rule, and 23 years of French mandate. The events that led to the creation of the republic became key elements in the structure of the country, its social services, and the explosive events that led to two civil wars. The French mandate laid the ground

for the forging of the constitution in 1926, and left behind an infrastructure that shaped Lebanon's system of law and justice, and influenced the set up of the armed forces, as well as several ministries and public social services.

The Lebanese government was designed as a 'confessional democracy' (*'confessionalism'* refers to the grouping of people by religion) (Encarta 2000). It was designed as multi-religious and multiparty, with political power and government bureaucracy organised according to religious groups. Other political positions were also assigned to particular sects; the constitution and National Pact of 1943 specified that the President be a Maronite Christian, the Prime Minister a Sunni Muslim, and the Speaker of Parliament a Shiite Muslim. Seats in the Parliament were allotted to the different sects and minority groups, weighted by percentage of the general population. Apart from the predominant Maronite Christian, Sunni Muslim and Shiite Muslim groups, the Lebanese population also contains several other minority groups, the following of which are recognised by the government, and have seats in the parliament: the Druze, Armenians, Orthodox Christian, Protestant Christian, Ismaili Muslim and Alawite Muslim. These divisions of power, and the subsequent growth of the size of minority groups, created demands for a redistribution of political power and a sectarian tension that led to a civil war in 1958, and launched the second civil war in 1975, which raged until the early 1990's. Herein lies one of the main reasons hindering the launch of a new national census as the process. The results are very politically sensitive and could have repercussions on the distribution of political seats and power at governmental levels.

The National Reconciliation Charter (Ta'if Agreement) of 1989 brought an end to most of the fighting of the second civil war, and introduced amendments to the constitution which were passed in 1990, and which allotted equal parliamentary seats to Muslims and Christians.

Political power remained only one of the causes of such tension among the people of Lebanon. Another major cause for tension has been economic disparities between the rich and the poor, which were made worse by the civil war. Christians and elite Sunni Muslims generally tend to be better educated, and dominate the upper and middle classes, while Shiite Muslims make up for a large part of the population (one third) that is considered poor. Although this economic distribution has been slowly changing in recent years, economic disparities still greatly exist, and the growing class polarisation remains the source of much unease.

Other groups that became economically beleaguered by the war were poor families from other parts of the country who migrated to Beirut, and people from Southern Lebanon who were displaced by the fighting. Both these groups are to be found clustered mostly in the suburbs of Southern Beirut. Another constant social issue since 1948 concerns Palestinian refugees who were displaced from their homes by the Arab-Israeli conflict in 1948 and 1967. This group has remained confined to unsanitary camps and denied any form of citizenship. The United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA) estimates the number of Palestinian refugees residing in Lebanon, that is, those that are registered at UNRWA, at 404,170 (UNRWA 2005), or an estimated 10 per cent of the total population.

## **Beirut**

The capital of Lebanon became a centre for Arab nationalist thought and the most cosmopolitan city in the Middle East as far back as the early 19<sup>th</sup> century. It was famous for being liberal and for becoming an epicentre where East meets West – it provided ample exposure to Western cultures for Arabs in the Middle East, and was a port of entry for the rest of the world.

Beirut has not only continued to be the commercial centre of the country, but is also consistently identified with the best educational and health services. These services, both public and private, are largely concentrated in the cities and on the coast, and in particular in Beirut.

Since the civil war, Beirut now contains more than half of the total population of Lebanon, including persons displaced from previously occupied or conflicted regions and who have found it difficult to return to their villages for a variety of reasons. Consequently, Beirut has become the largest city in the country by far, and is inhabited by people of every religious, ethnic, educational, economic and social group (Deeb 1997).

## **B. Post Conflict: public and social services**

The existence of such different groups and sects in the Lebanese population was also reflected in the schooling, which was once almost exclusively run by religious communities. They have also been one of the main providers of general social services, alongside non-governmental organisations (NGO's), which were mostly religious, communal or ethnic.

For several years during the last civil war in Lebanon (1975 – 1990), the government and its public services became greatly incapacitated, and social services were provided almost entirely by these NGO's and religious groups, as well as regional and international NGO's and UN agencies. These included medical, social and rehabilitative services, and quite frequently specific programmes for disability. Furthermore, the fighting created geographical barriers that prevented easy travel from one part of the country to the other, and this led to the establishment of additional local centres offering social services, sponsored by NGO's or others, all over the country.

Most of these organisations and their projects were supported by external relief funding, which ceased after the end of the war was declared in 1990-91. Those that were operating on a relief basis slowly phased out, or transformed into development NGO's, or gave way to main centres in each of the Lebanese governorates. External funding was also diverted to rehabilitate governmental infrastructure and services, a long and arduous process that continues today. Aside from the material aspect of such a change, it has also symbolically resurrected the role of the government and the public sector, and allowed for networking and coordination channels between the public and private development sectors. It is such networking and joint lobbying that promoted the recent 'Rights and Access of the Disabled' law (Law 220/2000) and contributed to its endorsement by parliament.

### **C. The Cultural Context: children and child-rearing**

The only source to be found on child rearing in Lebanon is a study that dates back to 1961 (Prothro 1967). Though it may be said that some of the general findings cited in this study remain in practice today, the wars that took place in Lebanon since the time of the study have affected societal practices and attitudes in several immeasurable ways.

Prothro studied six communities of varying religious and socio-economic backgrounds in Beirut and the Beqaa Valley. He found several common trends in child rearing between these communities, 'a certain homogeneity in this aspect of the culture' (Prothro 1967:155). Parents were found to be eager and thrilled at the prospect of having children, and the child was breastfed and indulged until his/her first birthday. After this point, the child is weaned, toilet-trained and a stricter form of rearing is adopted. Aggression is frowned upon and 'the good child is thought of as one who is obedient and polite, though this ideal seems to be achieved only rarely' (Prothro

1967:154). Dependency in children is accepted and even encouraged, though 'Lebanese mothers generally expect the child to behave independently at a fairly early age' (Prothro 1967:155), yet usually not before the child is five years old. Independent achievements by children, and the ability to take on responsibility, were considered signs of 'cleverness' and capacity that are greatly encouraged in Lebanese society. At the time of his study, Prothro attributed this to the country's rapidly developing economy and the enterprising nature of the Lebanese.

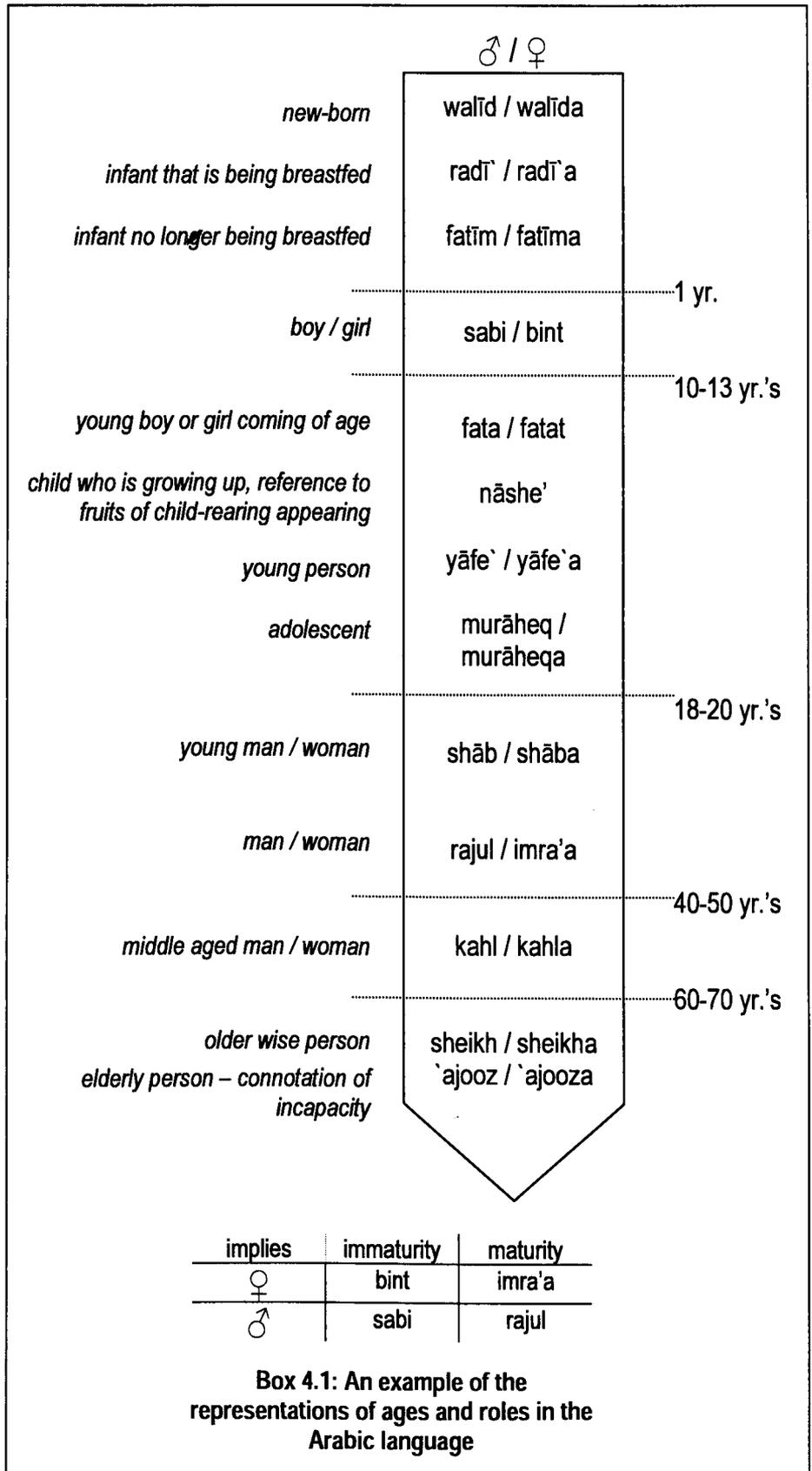
Language can offer some insight into how the child is represented and viewed in Arab societies. Language plays a key role in identifying children and childhood in two distinct ways. On the one hand, labels used to describe children and childhood provide insight into how they are socially and culturally perceived within any given community. On the other, language and conversation are also processes through which children learn about their social roles and positions.

The use of language to indicate the different stages of childhood is readily illustrated in the English language which continues to develop several terms to describe the metamorphosis of the newborn child into an adult: infant, toddler, pre-schooler, school-going age (which assumes that all children go to school), pre-teen, teenager, adolescent, youth, young adult. The first couple of terms were coined to highlight the child's needs, and the ones that follow fall into the formal structure of schooling and the child's stage in it. The term "adolescence" signifies a state of being neither as a child nor as an adult. It represents a physical maturity but social immaturity owing mainly to the prolonged 'childhood' of continued schooling.

In the Arabic language, there are fewer terms to describe the period leading up to adulthood, but those that do come to mind imply a social maturity (usually accompanied by a physical one) that carries a social

weight and responsibility. It is also gendered, with different names for females and males at certain ages referring to physical growth and social roles (see Box 2.1). Interestingly, this list of terms is constantly taught as a part of a longer one that lists the different namings of the ageing process.

These words for different stages, however, have



nuanced meanings of vulnerability, independence, capacity, maturity and wisdom.

The term “*radī*” is used in classical and colloquial Arabic to refer to the dependency on others, specifically a breast-feeding mother, for survival. To have a term for when that period ends, when the infant becomes a “*fatīm*” implies the first level of independence, though the child will continue to need support, protection and guidance as he/she becomes a “*sabī*” or “*bint*”. This period also carries meanings for bonding and familial identities, where infants breastfeeding from the same woman consider themselves brothers, as do children being reared together jointly by their mothers. This was not uncommon in a country like Lebanon until the last decade or so where bonds were made with neighbours similar to those practiced in villages with adjoining households of relatives.

As the children grow, the terms that accompany their stages of development imply an expected level of physical growth, maturity and behaviour, as indicated, though this is rarely relegated to decision-making processes where they are still not considered sufficiently knowledgeable or capable. For example, the term *bint* can follow a woman into a later age to imply that she remains a virgin, still carrying with it its connotations for immaturity or vulnerability and a need for protection. Some Arab countries, such as those in the Gulf, use the term “*jahe*”, which means “ignorant” in its literal translation, to refer to children, who are perceived to lack knowledge about the ways of the world.

The use of language, in conversation, not only displays social constructs and perceptions of children and childhood, but also showcases them to children in daily narratives. Phrases such as ‘acting like a child’, ‘childish behaviour’ and the like to describe someone who is behaving irrationally, have synonymous versions in other languages and implicitly attach meanings of irrationality and immaturity to children. ‘Act your age!’ implies that there are expected behaviours of specific age groups, and other proverbs such as ‘Children should be seen and not heard’,

though perhaps not taken as seriously as they once were, still circulate in conversations around or with children. There is similarly a wealth of Arab proverbs about children, all of which propagate similar meanings of immaturity, vulnerability and submissiveness. Some examples of these are: “*el walad walad walaw hakam balad*” – “a child is a child, even if he ruled a country”, that children will remain incapable and immature even if they were in a position of power; “*qadi el awlad shanaq halo*” – “the children’s referee/judge hung himself”, that children are irrational and do not listen to reason.

There are aspects of these representations and constructions that still exist to varying degrees in contemporary Lebanese society. The war in Lebanon would have more directly affected children who are now the parents of the children of today. Aside from the mass insecurity and unpredictability that war generates, the period in which they were growing children witnessed episodes of prolonged displacement and emigration which exposed them to several other practices and beliefs. It also led them to question some of their own beliefs. These have naturally all made their way into their currently held convictions and their rearing practices. As there has not been a study investigating these changes or comparing current child rearing practices to those that Prothro highlighted, it is difficult to pinpoint how the experience of the war has affected these people as parents.

As a Lebanese, I would suggest that rearing practices have slowly moved closer towards certain Western methods. Perhaps this is more relevant to urban settings where accessibility to current medical techniques, supportive equipment (baby monitors, breast-pumps, baby activity centres) and toys has greatly increased. I would argue that modern methods have also spread to other parts of the country by exposure to all forms of media and through more widespread higher education. However, it is also my observation that the ideal of the ‘good child’ has remained the same.

## **D. Policies concerning children and disability**

Lebanon has ratified the Convention on the Rights of the Child (CRC) and the government has co-operated with the corresponding children's rights projects that were set up by the NGO sector, and by the concerned UN agencies. In terms of policy, children are primarily addressed through education and labour policies. The former has specified a compulsory five-year primary school programme for all children, and the latter has specified a minimum age for legal employment of 12 years (with civil society movements attempting to raise it to 15 years) (Britannica 2000), (MoSA 2000).

Government policies in the health, social affairs and education sectors in Lebanon have recently started opening up to include and address disabled people. The Ministry of Public Health has, in recent years, set up a prosthetic and orthotics office in coordination with the World Rehabilitation Fund (WRF). Some of the main aims of the office were to maintain a register of physically disabled persons, and provide prosthetics, technical aids, or medical references towards their rehabilitation. However, it was mostly the advocacy and lobbying of local NGO's for disabled people that led to the passing of a 'Rights and Access of the Disabled' law. After years of drafting, the law was submitted by the Ministry of Social Affairs and passed by government in May 2000. This Law 220 addresses issues such as physical access, education, provision of social services and equal opportunity employment. It also extends to producing a national register of all disabled individuals, and creating a 'National Committee for Disability Affairs' which would include disabled people. The law is discussed in more detail in Part II of this chapter. It is worth noting here, however, that although the law highlights the responsibilities of the varied relevant sectors and cuts across them, it did not manage to break the traditional practice of assigning disability issues primarily to the Ministry of Social Affairs.

## **E. Disabilities & Impairments in Lebanon**

People with impairments exist in noticeable numbers in Lebanon. People have physical, mental and sensory impairments, with causes ranging from disease, accidents and war-injury to congenital and chronic illnesses. There are few sources of statistical data describing impairments in Lebanon, and the ones that do exist describe a specific sub-population and have become outdated. A Beirut-specific health survey in 1992-1993 (Deeb 1997) listed only the existence of physical and mental impairments amongst children aged 0 – 19 years, and no sensory impairments, whereas other recently published statistics (Younis 2000) have indicated that the number of people with auditory impairments alone has reached numbers as high as 15,000 in Lebanon. The fact that Beirut contains half the population of Lebanon, and that the under-18 age group constitutes 36% of the total population (UNICEF 2002), would imply that there could possibly be up to 2,700 children (under-18) in Beirut who have auditory impairments. Whereas the figure from the first source may be indicative of a limited area and method of data collection, the second figure provides better justification for the number of centres and programmes for sensory impaired people currently operating in Lebanon.

There are no official statistics for the number of visually impaired people in Lebanon, but organisations dealing with visual impairment have estimated the number at 6,000 (Youth Association of the Blind, personal communication, 2006). Statistics collected by the Ministry of Social Affairs suggest that people with visually impairments constitute 7% of an estimated total of 160,000 disabled persons in Lebanon, which would produce another estimated number of 11,200 visually impaired persons in Lebanon. This would, through a similar calculation to the one above, imply the possible figure of 2,184 visually impaired children (under 18 years) in Beirut.

As mentioned earlier, the process of conducting a census or a detailed statistical study of Lebanon is highly sensitive politically. As such, very limited statistical studies have been undertaken in the

previous years, and most of these focus on Beirut. Consequently, there are no immediate sources of official statistics measuring the prevalence of impairments in general. A current initiative to estimate this prevalence nation-wide has indicated the need for solid and creative mathematical modelling to account for the lack and inconsistency of data available at the local, governorate or national levels, as well as the continued discrepancies in defining and identifying impairments. Preliminary findings of this initiative have estimated the prevalence of impairments at 8% of the Lebanese population, without sufficient data to produce a similar estimate for disabled children (Sibai 2006).

As for children and disability; disabled children who are not restricted to their homes can be found in three specific settings: specialised institutions, integrative centres or community programmes, and inclusive schools. As in other parts of the world, the approach to disability in Lebanon evolved in that order (from institutions to inclusive schools), which accounts for the higher number of institutions in comparison to inclusive programmes.

While collecting information about visually impaired children in institutions, the data indicated that the children attending such institutions were mainly from families of low socio-economic status. Investigating this issue with a leading ophthalmologist in Lebanon indicated that the prevalent causes of visual impairment in children – consanguinity, lacking or incorrect pre- and post-natal care, and surgeries undertaken by unspecialised generalists – existed mainly among poorer communities.

## **Part II: Review of Social Policy in Lebanon Concerning Disabled Persons**

### **A. Introduction**

Social policies relating to disabled persons are normally implemented through a system of social services and welfare that works towards achieving the policy objectives. However, the truest reflection of a government's commitment to policy is often in the economic resources allocated towards the implementation of these policies.

Policy concerning disability and disabled persons also sheds light on the social construction of disability that is espoused by a government. This appears not only in the categorisations of disabilities and the methods employed for diagnosis and measurement, but also in the steps proposed towards putting the policies into practice. Adopting a medical model of disability will produce social services that are geared towards rehabilitation and normalisation and will be focused on aspects of care and welfare. A government that utilises a social, rights based approach will produce policies and legislation that safeguard the rights of persons with disabilities and focuses on non-discrimination and the provision of equal opportunities.

Social policy is a reflection of the socio-political and economic context of any country, so its design within that context also reflects the dominant social attitudes and practices. Policies may challenge the status quo but may have articles that approach the main objectives while appeasing potentially powerful opposition. Contrasting the policy to the measures that are put in place to implement it, within a certain period of time, will give an indication not only of the government's commitment to the policy but also of obstacles and challenges facing its implementation. These challenges may emanate from within the government agencies themselves or from society, and are usually entrenched in economic interests or prejudice.

## **B. Historical Background to Disability Policy in Lebanon**

Very little of the history of disability policy and practice in Lebanon has been documented. The first signs of a special policy for disabled persons appeared during the Ottoman Rule of Lebanon with a law in 1876 for “mentally ill” people that placed them in asylums. (Raad 2000): 3). This remained the practice until the fall of the Ottoman Empire after World War I. There are no indications of a different policy having been instated during the French Mandate which extended from that time until Lebanon’s independence on November 22, 1943.

The absence of any policy concerned with disabled persons ended with the emergence of Law 11/73 (31/Jan/1973) concerned with “Caring for the Handicapped”. This came about as part of a social reformist sweep in the 1960s headed by the post-1958 revolution President Riyad Shehab. The law provided a definition of mental and physical disability but continued to adopt a social welfare approach of treatment, care and protection that is reflected in its name. The war broke out in Lebanon shortly afterwards, with incidents occurring as early as 1974, and the law was not passed by government until 1983, where it also stated that an administrative body should be created to propose and monitor projects supporting the law (Raad 2000): 3). The civil war in Lebanon finally ended in 1992, and it is doubtful that the government was able to put the 1983 law into practice amid the ongoing strife of Israeli incursions, civil warring and the assassination of presidents and prime ministers.

Ten years later, within the upsurge of post-conflict social reform, the government passed a new law to replace Law 11/73, and this was Law 243 (13/July/1993) on “Handicapped Rights”. This law reflected the input of a disability movement that had emerged during the war, as well as related international documents developed by UN agencies. Law 243 provided a new definition for disability that fell in line with WHO guidelines, but it was also the first to speak of the principle of rights of disabled persons, and the first to extend a concept of partnership. The law called for the

formation of a National Council for Disabled People (NCDP) consisting of representatives from the Ministry of Social Affairs (MoSA), the large social welfare institutions and disabled people's organisations, while stating that 'the government is responsible for all scientific, vocational, health and social affairs for the disabled, in cooperation with public offices, the private sector and international organisations' (Saqr 1999): 3). The NCDP was expected to become a consultative body that would recommend policies and legislation to MoSA for turning the law into practice.

Though both laws called for the formation of a National Register of Disabled Persons, and the distribution of disability cards, the work towards completing these tasks was never fully nor appropriately completed. Law 243 also called for community-based approaches, which were few and short-lived for various reasons; such as inadequate training, poor awareness raising, inappropriate distribution of funds and other; and none of which were actually initiated by public centres. Under the influence of these two laws, and the situation that ensued after the war in Lebanon, the government's implementation focused on supporting institutions and subsidising residential services for disabled children and adults. This was a continuation of a charitable practice which had started during the Ottoman times with a number of missionary and other religious organisations, and continued throughout the war when geographical lines were drawn on a sectarian basis. Some stakeholders assert that the system that was adopted by MoSA was actually a response to this traditional practice. Faced with its new task to address disability issues, it found the most appropriate path in doing so was to support the existing institutional structures.

*Stakeholder A (representative of a disabled people's organisation): The base is the system. MoSA did not create this system, it developed a system that responded to this base. It looked to find all these institutions present and said, let me help you. So MoSA is a subsystem of the system.*

Studies on social welfare in Lebanon conclude that the main actors in the field are indeed the local institutions and NGOs – *'Those who in effect control social welfare are NGOs – and predominantly local ones at that. The sector has free rein in the elaboration of programmes and little internal*

*coordination. Moreover, all of the social care services provided by the Ministry of Social Affairs are contracted through local NGOs' (Jawad 2002): 324). As most of these organisations are either religiously or politically affiliated, their programmes fall into socio-political agendas as well as representing the economic interests of individuals or groups. Thus the implementation of social policies concerning disability are pursued within the interests and priorities of these groups. This falls in line with the overall system of power in Lebanon, as the government is based on a sectarian system, and sects have become linked to specific political parties since the beginning of the war.*

Indeed the rationale behind the work towards Law 243 was overtly seen as a political move at the hands of a newly appointed Minister of Social Affairs. Elie Hobeika was a militia leader during the war who became Minister as part of the post-war reconciliation and negotiations, along with many other militia leaders of other political parties. Hobeika's support of a review of Law 11/73, which had become invalid, was seen to be fuelled by his realisation that the disability issue would 'rejuvenate his reputation damaged as a result of his wartime activities as a militia leader' (Kingston 2004): 4). His support was crucial in the development of the law with its emphasis on rights and partnership, and no doubt facilitated the process of passing the law within the parliament.

However, the post-war government was entrenched in a process of economic and infrastructural reconstruction and the implementation of social initiatives fell by the wayside. Perhaps the NCDP was established in anticipation of such a possibility as it continued to work and lobby for the revision of Law 243 in the format of one that would promote a Rights and Access programme that focused on liberties, rights and quality of services for disabled persons. As such, approving Law 243 had launched a dynamic that would soon culminate in a newly drafted "Rights & Access for the Disabled" law which would be passed by parliament in May 2000. The terminology of the titles of the three laws alone reflects the evolution of thought and perspective from service, needs and

care to rights; as the language moved from “Caring for the Handicapped” (1973) to “Handicapped Rights” (1983) to “Rights & Access for the Disabled” (2000).

### **C. Regional Context of Disability Legislation**

Disability legislation has been very slow in the making in the Arab region. Only a handful of countries have developed or passed disability laws, and others have only made slight considerations for disabled persons in existing legislation. This movement for appropriate legislation was given an impetus in the region by the *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* (WHO 1993) in the early 1990's and is now being guided by the current process of developing a final draft of the UN Convention for the Rights of Disabled Persons. Work on the UN Convention has shed light on a number of issues that have not been taken into consideration in regional legislation, particularly in discussions of the Ad Hoc committee in New York. To illustrate, a meeting that was held in January 2006 witnessed much resistance from disability advocates or representatives from the region who had not previously contemplated issues related to birth rights, family rights and legal capacity, specifically as pertaining to persons with non-physical or mental disabilities.

A brief review of disability laws where they do exist in the region, and where they are available for examination (Bahrain, Jordan, Morocco, Oman, and Yemen), indicates a general focus on rehabilitation, prevention and accessibility, with varied emphasis on non-discrimination and rights. Few of them highlight mechanisms for implementing the law, and those that do place that task with a national committee for disability affairs, traditionally assembled within Ministries of Social Affairs or their equivalent (Independent Living Institute 2000). The most comprehensive of these resembles the main sections of Lebanese Law 220, a law that is considered one of the more

advanced in the region and has been used as a model in countries that are currently developing their own disability laws.

## **D. Current Disability Law – Law 220/2000 ‘Rights & Access for the Disabled’**

Law 220 was submitted to the government for review and approval in December 1999 and was finally passed by the parliament in May 2000. It came as a result of several years of lobbying by the NCDP and other disabled people’s organisations, and finally came to pass during the government of Prime Minister Salim El Hoss, which was coincidentally largely formed of technocrats that were appointed as ministers, circumventing the usual electoral process for becoming members of parliament and then being assigned ministerial duties. Upon closer inspection, Law 220 illustrates the influence of the *“World Programme for Action Concerning Disabled Persons”* (UN General Assembly 1982) and the *“Standard Rules on the Equalization of Opportunities for Persons with Disabilities”* (WHO, 1993).

The main contents of the law are as follows:

Section 1: Terminology, Definitions, Categorisations, and the Disability Card	Articles 1 – 5
Section 2: National Committee for Disabled Affairs	Articles 6 – 26
Section 3: The Right of the Disabled Person to Medical Services, Rehabilitation and Support Services	Articles 27 – 32
Section 4: The Right of the Disabled Person to an Adapted Physical Environment	Articles 33 – 43
Section 5: The Right of the Disabled Person to Transportation, Parking and Driving Licenses	Articles 44 – 54

Section 6: The Right of the Disabled Person to Housing	Articles 55 – 58
Section 7: The Right of the Disabled Person to Education and Sports	Articles 59 – 67
Section 8: The Right of the Disabled Person to Work, Employment and Social Security	Articles 68 – 82
Section 9: Miscellaneous Tax Rules Relating to the Disabled Person	Articles 83 – 94
Section 10: Miscellaneous and Concluding Rules	Articles 95 – 102

Law 220 defines a disabled person as (article 2):

*'A person who has decreased or absent abilities to: pursue one or more important life activities, or obtain his/her needs by him/herself, or participate in social activities at an equal level as others, or ensure a normal personal or social life as per the dominant societal criteria, and that is due to loss or impairment of a physical, sensory or mental function, partially or fully, permanently or temporarily, occurring at birth or acquired or due to an illness that lasted longer than it medically should.'*

The law also goes on to specify that any person falling within the WHO categories of disability that are employed by the law would be eligible for the Disability Card that needs to be applied for personally. Articles of Law 220 are then applicable only for holders of the Disability Card. The law also contained incentives to encourage the implementation of its articles. These included exemptions from taxes as well as penalties and fines for failure to comply with the contents of the law.

It is of note that the longest section, that is the one containing the most articles, is that concerned with defining the role, tasks and organisation of the National Committee for Disabled Affairs. A few issues worth highlighting regarding this committee are as follows:

- The law specifies that the committee is a consultative body responsible for recommending courses of action in support of the law and in accordance with its tasks, and the MoSA is the executive party responsible for implementing these recommendations.
- Membership to the committee is constituted of four members from MoSA who are automatically assigned due to their posts; namely, the Minister, the Director General, the Director of Social Services, and the Head of the Disability Affairs Office;

Four members from disabled people's organisations representing the four disabilities (physical, visual, auditory, mental) who are elected to their posts by holders of Disability Cards,

Four members representing service institutions, elected by their peers,

Four disabled persons representing themselves, and falling into the four disability categories, elected by holders of Disability Cards,

Two members appointed to the committee by the Minister in light of their expertise in a field that serves to support the role of the committee.

- The National Committee for Disabled Affairs is considered a permanent body, with elections held every three years to allow for the nomination of new members.

The detailed articles that outline its role and modus operandi, draw parallels with those required in constitutions of registered organisations, and are considered legal steps towards safeguarding its effective operation and sustainability (Saqr 1999): 8).

The law also took several measures to address prior discriminatory legislation that prevented disabled persons from registering in vocational training centres, or applying for employment. Law 220 is a revised version of Law 243, with adjustments and modifications introduced to circumvent legal and practical obstacles that had faced the first law. For example, whereas Law 243 asserted non-discriminatory principles, it did not address opposing articles in other legislation dealing with social security, education, labour and others. Law 220, on the other hand, pinpoints several of these other laws and declared their conflicting articles null and void.

Other new issues that were raised by Law 220 dealt with housing and the accessibility of the physical environment, which were not previously included in any other legislative framework in Lebanon. The law proposes that a building code of minimum standards be developed by the National Committee and is then included in the legal conditions for contractors. Furthermore, the law not only specifies that all public buildings and new construction must be accessible, but also asserts that all new housing projects must set out sections that are available for purchase by disabled persons.

The new law is lauded for being the first of its kind to strongly and clearly address issues of discrimination towards disabled persons. In each of its sections, it is asserting that all aspects of daily life and governmental decision-making must take into consideration the segment of the population that is disabled. As such, measures such as employment quotas and housing allocations and loans are considered stepping stones towards equal opportunities for disabled persons.

Where children are concerned, the main section that directly addresses them is that of education and sports. The section details the right of all children and adults to be admitted into all schools and educational centres, and proposes measures for adapting formal examination formats and schedules to be suitable for each student. It also asserts steps towards raising awareness among the student population as well as training for the teaching staff. In terms of exemption from fees, article 61 in this section specifies that fees for tuition, sports, social activities and medical needs will be covered by the government for all students choosing to attend a specialised centre or institution, a request that is processed through applications submitted and approved by the MoSA.

Within *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (WHO, 1993), the fundamental concepts of disability policy are listed as (a) defining disability and using the appropriate terminology, (b) prevention, (c) rehabilitation, (d) equalisation of

opportunities. They are the principles that appear throughout The Standard Rules and are considered essential parts of any policy on disability. In reviewing Law 220, it is clear that the final draft included all of these principles in its articles and sections.

## **E. Problems of Implementation of Law 220/2000**

Law 220 still exists without any decrees outlining modes of implementation. The law specified that each of the Ministries of Health, Education and Labour were to form technical committees to look into ways of translating the law into practical steps and to formulate the corresponding decrees within a year of passing the law. Other concerned ministries were encouraged to follow suit. This process was continually delayed, in part possibly due to the frequent change of government and ministers, and partly due to a general resistance to the law and the changes it implies.

The intrinsic weakness in Law 220 is that it extended its articles to a number of ministries, yet laid the executive responsibility upon the Ministry of Social Affairs. Though the law itself was passed by Parliament, measures related to the responsibilities and tasks of any specific ministry that are not endorsed by the Prime Minister's government do not carry weight, especially those that call for drastic changes in systems and practice. Indeed, placing the coordination of the law in MoSA restricted the span of influence of the National Committee for Disabled Affairs, and limited the effective involvement of concerned government agencies. It also identified the law and all affairs related to disability and disabled persons as synonymous with MoSA responsibilities rather than transforming the perception to recognise that disabled persons possess these rights within the realms of all the other ministries as well.

In its affiliation to MoSA, it is not possible for the National Committee for Disabled Affairs to play the role of ombudsman or 'watchdog' to violations of the rights of disabled people as asserted by Law 220. This has, in effect, left disabled persons without proper and official advocacy representation outside of the previously existing disability movement. Ironically, with the existence of the National Committee, the disability movement's influence on government affairs has become weakened as it is no longer considered the main voice of disabled persons as it was in the past. Additionally, the National Committee has failed to represent essential partners in the process of implementing the law, such as schools, parents' organisations and others (Saqr 1999): 8). The representation of children and their interests is also very weak, being restricted by proxy to representatives of social institutions which, out of the members of the National Committee, are the only parties working directly with children. Thus, though the design of the committee broadened the spectrum of membership from the NCDP (its predecessor), its proposed structure has in effect excluded part of the disabled population.

*Stakeholder S & F (representatives of a disabled people's organisation and parents' organisation respectively): And that is one thing that is grossly lacking in the set up in Lebanon – we don't have our own organisations in the governmental system. That is, we don't have a body that looks out for our interests rather than political interests*

This sentiment is echoed among other disability activists who were, in fact, involved in the process leading up to lobbying for Law 220, but have since found themselves not properly represented in the executive teams and decisions. Though they themselves admit that there are other schools of thought among the disabled population in Lebanon, what they continue to demand is an equal opportunity to participate in the decision-making process that directly affects them.

*Stakeholder A: The percentage that we represent are people like us. The rest are lost between the institutions and specialized centres and the like.*

*Stakeholder S: ... we want it to be "Nothing about us without us", regardless of whether you are with or against us. The structure of society is made of many elements and pieces, we must be recognised as one of those elements. It is our right to participate in putting together the programmes and policies that concern us. We need to get to a point where our opinions count in these respects.*

*Stakeholder F: We want to simply say “STOP! We don’t want anyone to make decisions for us”. We need our respect. We need our opinions to be respected.*

However, what these stakeholders note as one of the main obstacles in working for their rights to participate in schooling, employment and society at large is the widespread lack of awareness and ignorance about disability.

*Stakeholder F: People’s knowledge and attitudes are still grossly ignorant. Parents [of children with Down Syndrome] we work with tell us that people ask them what medication they took, or what mistake did they make such that they had a child with Down Syndrome!*

*It’s like that priest who saw me in the hospital with my two youngest children while they were waiting to take their shots. He gave me a piece of candy for each child, but then when he saw (her daughter) and saw that she had Down Syndrome, he took back her piece of candy and said to me “she who lives such a life has such children” (implying that the daughter was a cursed punishment for her mother’s sins).*

*Stakeholder S: My mother had to hide me from the neighbours. They insisted that I should be taken away to a hospital and had brought an ambulance to take me away, and my mother ran off with me in her arms into the fields behind our house.*

Unfortunately, Law 220 does not contain any suggestions for awareness raising programmes that would address the society at large, nor does it actually contain provisos for adequately publicizing the law itself among the general public.

In spite of this law being cognisant of the fundamental concepts of disability policy, including prevention and rehabilitation, it has overlooked instating measures for early identification and intervention. This frequently leads to missing the window of opportunity in the critical period of children’s development to introduce essential interventions which would greatly contribute to their rehabilitation, as well as providing opportunities for self-empowerment. Neglecting early identification and intervention may be due to the overall focus on disabled adults, which appears in several sections of the law as well as general research that has been conducted on disability in Lebanon. Omitting parents and their organisations from the processes of this law reflects a gross oversight on taking children’s issues into consideration. In the absence of the representation of

schools as well, it relegates all issues and decisions pertaining to disabled persons under the age of 21 to the concerned professionals in the medical field, in social welfare centres and institutions.

Despite all adopted precautions to ensure non-discrimination, some of the proposed measures in Law 220 were only a slightly evolved form of the traditional discriminatory attitude towards disabled persons. A case in point is the section on housing which, though it suggests methods for facilitating housing loans, proposes creating separate housing for disabled persons within housing projects (article 55). These buildings are also to be tagged with the universal disability sign (article 55.d), which for all intents and purposes will serve only to create ghettos of disabled persons. Whereas including this section in Law 220 is an improvement on the total absence of this issue in previous disability laws, the final format may not be empowering to disabled people in practice.

All in all, Law 220 contains a new rights-based perspective on disability issues, and promotes a new social construction of disability that falls closer to the social model than the traditional medical model. However, the subtext of the larger part of the articles still subscribes to a needs-based perspective of disability, or easily allows for that interpretation within the bounds of the law. Article 61 of the section on education asserts that all fees will be sponsored by the government for children registered in specialised institutions, promotes segregation and exclusion, which are the current dominant practices, and works against the concept of inclusive education that is raised in articles 59 and 60. Article 62 concerned with the adaptation of formal examinations as per the needs of disabled students has been interpreted as setting up separate examination centres within specialised institutions. Formal examinations follow a standardised, centralised process which deliberately assigns students to different examination centres to safeguard against cheating or discrimination. Setting up separate centres especially for disabled students not only questions the honour code employed by the examiners and the students during examination, but is also exclusionary, and confirms the perception that these are special students. Consequently, as with other social services and systems in the country, this initiative is 'grappling with modern concepts

of development and at the same time remaining faithful to... traditional value-systems' (Jawad 2002): 338).

### ***Law 220 in Practice***

In the six years since the passing of the law, not one of the measures that it proposes has been completed. Of the three technical committees responsible for formulating decrees to implement the law in their respective ministries, only those in the Ministries of Labour and Education have been formed. The latter was finally assembled in 2003 but continues to exist without a decree providing it with any executive role or power.

Many other government agencies remain unaware of the law or continue to fall short of implementing it. Customs taxes are still being paid on specialised items for disabled persons, such as wheelchairs, adapted cars, or educational equipment and material, all of which are meant to be exempt from customs taxes under Law 220. The de-centralised network of municipalities, that falls under the authority of the Ministry of Interior, and is responsible for approving building and urban design permits remain unaware of the law and its provisos for accessibility (Lebanese Physical Handicapped Union 2004): 6).

Moreover, as the only people entitled to claim any of the rights highlighted in Law 220 are those who carry a Disability Card, it appears that registration for the card is also inadequate. In the last published "*State of Children in Lebanon*", the Child Rights Country Report for 1998 (which was prepared in 2003 by the Higher Council of Childhood, which is attached to MoSA) lists that the total number of children under 18 years of age who have registered for Disability Cards is 10,602, making up 28.85% of the total number of Disability Card holders (Higher Council for Childhood 2004). By using the latest data available on disabled people in Lebanon, they have been found to approach 8% of the total population of Lebanon, an approximate 4 million. That is, 320,000

people in Lebanon are disabled. Calculating 28.85% of that figure brings a total of 92,320. If we were to use UNICEF data which asserts that approximately 36% of the population is under 18 years of age (UNICEF 2002), this would imply that the number of disabled children in Lebanon within this age group is 115,200. In either case, the number of disabled children far exceeds the number that has been registered for a Disability Card, which would infer that there is a gross under-registration for the Disability Card, in turn leading to the misrepresentation of disability issues through the formally set up channels, and an extremely limited outreach of benefits to the rights holders. The theorised reasons for this under-registration have varied from a lack of awareness of the existence of the law, to the shameful stigma preventing individuals or their guardians from registering for the Disability Card.

As the steps and plans for putting the law into practice unfolded, several obstacles that had not been accounted for appeared. The experience with the Ministry of Labour is an example of this. After a year-long awareness and advocacy campaign by disabled people's organisations, which were not represented on the National Committee for Disabled Affairs, the Ministry of Labour assembled its technical committee and drafted the corresponding decrees by early 2003, but these were then halted due to financial issues. One of the responsibilities attached to the Ministry of Labour was in processing loss of job compensation. These need to be processed by the Ministry of Finance, which has, up until this time, refused to do so. When the Minister of Social Affairs was questioned about the delay in implementing these decrees, his response was *"It has to do with the financial aspect of agencies, the same as everything else in the country, I don't exactly know..."* (Haidar 2003). In the end, many of the practical steps towards implementing the law came down to the issue of finances, and to the Ministry of Finance in particular. The national budget has not as yet any budget line items supporting the implementation of the law, and these would include subsidising rehabilitation and prosthetics by the Ministry of Health, allowances for renovations for the accessibility of physical structures to public schools and buildings, training staff and so on.

Even penalties from the private sector for violating clear articles of the law cannot be received because they require an income budget line item, and this has not been established.

There does not appear to be a will to challenge the existing status quo. The rationale for this seems to be both economic and political.

*Stakeholder S: A lot has been invested in the current situation (in terms of policies and set up). Many people have invested in the institutions and specialized services.*

*It reminds me of people like (a politician's wife) telling us that there is some fund we can obtain money from her organization for our programmes, as long as we don't spend it on addressing public affairs.*

*The MP's are also affected by this trend. When we were lobbying for law 220 to be passed, any time we would meet with the MP's by themselves, they all supported our concepts and reasons for having the law. And yet, in any one meeting of MP's, they would not say a thing, and not support it at all. There are a lot of interests at stake, a lot of interests involved overall, and politicians just exchange interests where they can.*

However, after reports being issued by the Ministry of Social Affairs, the country report and its recommendations prepared by the Higher Council for Childhood, and a peaceful protest of over 2000 people representing disabled people's organisations and human rights organisations that assembled in front of the House of Parliament on June 16, 2004, the regular meeting of the Prime Minister and ministers that took place on July 1, 2004 requested that *'a ministerial committee be formed headed by the deputy Prime Minister and to include the ministers of Economics, Commerce, Labour, Public Health, Social Affairs, Youth & Sports, Education & Higher Learning to study the report prepared by the Ministry of Social Affairs on implementing Law 220 dated 29/5/2000 related to the rights of disabled people, and to submit its report to the Prime Minister's government within two months at most'* (Annahar 2004). This was a very positive and hopeful step towards implementing Law 220, and showed the government's commitment towards activating the law.

Sadly, this initiative was brushed aside when the parliament reconvened at the end of that summer. The issue, along with several other social issues, was displaced by an intense political

battle concerning altering the constitution in order to allow the Lebanese President the exception of extending his time in office for a three-year half-term. This struggle polarised the house of parliament and effectively suspended all but the essential government decisions as the extension was forced through, and was followed by the Prime Minister's resignation, a course of action that automatically dissolves government and requires the formation of a new one. As 4-year elections were due to be held in the summer of 2005, the transitory government of ministers that was appointed effectively had less than a 12-month term, thus its focus shied away from decisions that only produced long-term impact. To further exacerbate the situation, the assassination of ex-Prime Minister Hariri in February of 2005 placed the country in a state of emergency; the transitory government resigned and was replaced by an 'emergency' scaled-down government that took office for the few months remaining until the scheduled elections.

The ensuing events had great impact on the stability of the country, and naturally on the intense focus allotted to internal and external geo-political issues. It was impossible during this time to raise the issue of disability rights and the implementation of the law. Months later, at a regional symposium initiated by the UN Special Rapporteur on Disability and hosted at the House of Parliament in Beirut in December 2005, the opening speeches by the Speaker of Parliament, the relevant ministers or their representatives were supportive but reverted back to nuances of welfare and charity. Ironically, the onset of the conflict with Israel in July 2006, and the ensuing injury-related disabilities caused by bombings or by exploding cluster bombs that continue to clutter the targeted areas of Beirut and the South, have placed disability issues back on the national agenda for recovery. Though the focus has fallen within traditional aspects of rehabilitation and victim assistance primarily for people with resulting physical disabilities, the existing inclusion and rights movement is also raising other rights issues at every opportunity.

Such times of political tension and instability are not uncommon for the region. The fact that the rights of the vulnerable groups, such as children or disabled persons, are ignored or not deemed

adequately important for active attention during such periods reflects that these rights are not yet intrinsically respected within the governmental system of decision making, whether a law exists or not.

## **F. Conclusion**

In addressing research question 1 - To what extent do current policies and practices in Lebanon foster inclusion versus exclusion of disabled children under 12 as part of a rights based approach? – the findings show that Lebanese legislation and policy concerning disabled persons remains broadly exclusionary, despite the rights based rhetoric that has been adopted. This indicates that legislation without implementation in resources, policies and incentives is largely ineffective.

The analysis has indicated that Law 220 contains a number of contradictory measures. The broad by-line of its sections call for the rights of disabled persons to medical services, employment, education, recreation and housing with considerations of access to the physical environment and transportation, but these rights are then interpreted by concepts of services and allowances that carry traditional, discriminatory constructs of welfare and needs. The expressed intention is to avoid segregation, while the actual practical measures subscribe to modified versions of labelling and surveillance; as marked housing, employment quotas, special education classes and disability card holders. Therefore it is unclear if Law 220 can promote inclusion.

Additionally, the lack of implementation of Law 220 in the years since its approval by parliament in 2000 demonstrates the governmental system's refusal to adopt even the most minimal changes required to address disability issues, that is, any changes to the public and private structures. As a relatively young state since its independence from occupation and foreign mandates, Lebanon

has taken great strides in developing comparatively progressive social policies. However, despite the consistent and steady process of evaluation and review undertaken by civil society, these legal advancements have occurred in specific times of reform and relative political tranquility. New legislation for disabled persons is no exception. Such laws do not only require legal and financial commitments and changes on the part of the government and its services, but these also have to address existing welfare-minded systems and attitudes. At the present time, Law 220 has done neither.

The current disability law in Lebanon promotes the rights of disabled persons rather than their need for rehabilitation and care. This approach is in almost direct opposition to a powerful ongoing tradition of institutionalisation and care, and dominant discriminatory attitudes in society. In the text of the law itself, economic allowances have been maintained for institutionalisation, other essential steps that would contribute to altering the status quo are not specified. Despite arrangements being made to allow visually impaired students to sit for official examinations, their teachers at BAL do not trust the resulting grades and remained sceptical of affirmative action measures that had started to appear as a result of Law 220/2000. In other sections, such as that discussed concerning housing, deep-rooted ideas regarding segregation are blatant. The text itself appears to be the outcome of a struggle to find compromises between the existing systems and the international conventions that the government has signed and agreed to ratify. Passing the law is considered a victory by disability activists who had lobbied long and hard for the beginnings of a qualitative change in the perception of disability in government agencies. It is clear that this transformation remains in its early stages, and though lobbying for the implementation of the law has not been facilitated by current political events, it continues to provide a foothold from which additional advocacy for change may be launched. This is needed as the lack of any engagement with the law by several ministries, specifically the Ministry of

Finance, indicates that the rights of disabled persons remain marginalised within the government's agenda.

The making of this disability policy has become the subject of studies regarding governance in Lebanon (Kingston 2004) due to its pioneering nature. The advocacy process and the organisation of the people's lobby resulting in a positive outcome are not common occurrences in Lebanon. However, the under-registration for the Disability Card and the lack of awareness in government and community circles about the existence of Law 220 show that the government would be remiss to focus solely on the existing structures, as it has so far within the text of the law, and not pursue the involvement of the public and society at large.

It is clear that the practices in the aftermath of this current legislation remain grossly exclusionary for disabled people and more so for disabled children. The law subscribes to a rights based philosophy but has translated this into articles that effectively create parallel systems for disabled persons, and removing physical barriers. Both of these thrusts have not actually challenged the existing structures of control and surveillance nor the pervasive power relations entrenched at every level. Disabled people have been moved from being marginalised in society to being marginalised in policy. This is evident from the resistance to change within governmental agencies, and the fact that the law has actually reduced the influence of grass roots lobbies through creating a National Committee on Disabled Affairs, and diminished the representation of disabled persons through the mechanism of registration for a Disability Card. It could even be argued that establishing a specific law for a specific group continues to view them as a separate minority.

A rights-based approach would, in practice, impose a change in the balance of power and the nature of power relations. This approach of rights as universal, indivisible and inalienable can compel policy makers and providers to alter their perceptions of disabled people from 'users' to

'rights-holders', from 'addressing the needs of many' to 'ensuring the rights of all'. In effect, such an approach would intrinsically need to allow for channels that would challenge the hegemony of the state and legitimate authorities in promoting individual rights.

Legislation on its own cannot foster inclusion. Legislation and policy need to be backed up with social measures at the field level that actively work towards re-defining disability in the society, and with capacity building of all service providers in order to recognise the necessary shift in their roles with disabled persons. Additionally, disabled persons must be empowered, as individual and as groups, to act as 'watchdogs' monitoring and lobbying for the promotion of their rights.

Law 220 was the result of lobbying by the disability rights lobby within the country and although they influenced the Law, they did not prevail in terms of the Law's implementation with resources. It is unclear how much the lack of implementation is affected by the continuing conflict and political instability that has weakened the state, or how much of it is a reflection of the legislation not reflecting the values and priorities of mainstream social groups in Lebanon.

This has resonance regionally and internationally where disability laws are being introduced or revised. The Lebanese Law 220 is being adopted with slight variations by a number of countries in the region, including Syria and Bahrain, where similar difficulties in implementation may be faced. In countries like Britain, disability laws or acts are being revised to introduce measures of enforcement outlawing any form of disability discrimination. Drawing on the analysis of Law 220 as a law that failed to institutionalise penalties or tax breaks, these measures introduced by European laws should result in a gradual restructuring of services and an eventual change in social attitudes.

Within a Foucauldian approach, it would be argued that change can only come about through a process of resistance that transforms power relations. In the light of studying Law 220, and the

geo-political forces and circumstances that continue to prevent it from changing, there will not be any real rights-based changes towards inclusive practice, regardless of the legislation and policy that is drawn up, until disabled persons are empowered to take a leading role in the system, and participatory systems of accountability to ensure implementation of legislation are introduced and respected. Additionally, this should not be limited to government level processes, such as the National Committee for Disabled Affairs, but rather specifically at regional and local levels involving users, parents, service providers and professionals.

The next chapter will focus on the organisational ethnography of the institution and will extend understanding of practices of exclusion and inclusion at this level.

# CHAPTER 5 – PROCESSES OF EXCLUSION & INCLUSION IN THE INSTITUTION

## Introduction

This chapter addresses research question 1, concerning the extent to which current practices in Lebanon foster exclusion versus inclusion for disabled children. Whereas in Chapter 4 this was explored at the national level through an examination of legislation and policy, in this chapter the question is addressed at the institutional level through an ethnographic case study of an institution for visually impaired children. This chapter also presents an analysis of data to address research question 2; the mechanisms and processes that allow the voices of severely visually impaired children in residential institutions to be heard. It does so through an analysis of a number of factors that impinge on the processes of inclusion and participation within this institution; mainly the organisation of space and time, structures of formal and informal authority and power, control, participation and resistance of parents, and the educational principles of the institution.

The argument is constructed utilising theoretical approaches drawn from symbolic interactionism as pioneered by Goffman, to analyse social interactions and processes within the institution that foster or prevent participation, and that also draws on a Foucauldian approach to power, control, surveillance and resistance in the analysis of the social structure, hierarchies and organisation of the institution studied. The argument set out in this chapter is that structural mechanisms promoting the participation of children will foster resistance to control in the institution, and lead to inclusive practices.

'Exclusion' in the education of disabled children is used to represent the opposite of 'inclusion' as has been described earlier. That is, it refers to a setting that is discriminatory to disabled children by making educational opportunities possible only through alternative and adaptive measures

being taken by the children and their families, without any changes being introduced into readily available, nearby educational settings, thereby rendering them inaccessible to the children. An extreme case of 'exclusion' has thus been cited as that of institutionalisation, where the educational setting offered to disabled children is geographically separated from their non-disabled peers, their families and society.

Goffman's analysis of a mental hospital as a 'total institution' (Goffman 1961) is relevant to the analysis of prisons, hospitals, residential institutions of all kinds, and is drawn on in this chapter. Within his definition of a total institution described in the literature review (Goffman 1961), this School for the Blind (BAL) can be categorised as an exclusive setting. For most children it is a total institution but around a quarter of the students leave the grounds at the end of the day. However, the question here does not refer to this type of geographical, physical or educational categorisation as much as it attempts to look into the ethos that is being propagated by the formal and informal settings at the school. Do the school and its staff promote an inclusive approach paving the way to the later social integration of its students?

In analysing its ethos and practices, three main themes emerged from the data that are explored in this chapter: the physical and social space, the formal and informal organisation of authority and power, and the values and rewards as perceived by the school population.

The physical space refers to the actual environment around and within the school. This section considers the school grounds within the context of its surrounding environment, as well as exploring the design and distribution of the space within the school and the general locus of motion and privacy consequently accorded to the children. This is referred to here as the social space.

Looking into the formal organisation of authority and power analyses the visible decision-making structures at the school – with staff, parents and students. What becomes more interesting is the

level of importance assigned to these formal authoritative structures, as well as the informal organisation of power that uphold them, challenge them or elude them. It follows that the values and rewards as perceived by staff, parents and students are directly linked to the formal authoritative structures, and the informal organisation of power and influence.

In broad terms, the formal setting refers to all the established aspects of the institution – in terms of geography, time-tabling, curriculum, population, economics and organisation. These are all considered relevant to the make up of the formal structures of authority and governance, control and surveillance.

The 'formal' and 'informal' structures and mechanisms of the institution are not mutually exclusive. Exploring and juxtaposing the informal pathways and contrasting them with the formal channels sheds light on the values and beliefs system that the formal structure propagates. It also sheds light on the perceptions and social constructions of the children's disabilities within the institution and, on the models of disability adopted and promoted among the children. This analysis shows how these factors contribute to the children's self-perception of themselves and their disability.

The argument set out below and evidenced by the data is that systems may nurture a dependency that stifles resistance or change. This will restrict the agency of children and parents within the institutional structure, thus maintaining status quo power relations and accentuating social stratification and roles.

## **Part I – Space & Time**

### **A. The Physical Environment**

The geographical location and physical environment of an organisation or institution can predispose it to an atmosphere of openness and connectedness to the surrounding community and environment, or can alternatively imply detachment or separation. This naturally reflects on the members or residents within the organisation as well, and affects how they view themselves as part of the establishment.

Furthermore, the physical structure is an indivisible part of the social experience of children. As argued by Wolfe and Rivlin, 'one cannot be without being in some place. The physical environment, the social structure within which it is embedded and which it supports and reflects, as well as its symbolic meanings determine to a large extent the kinds of experiences children have and what they learn about the world.' (Wolfe and Rivlin 1987): 89-90).

The BAL School for the Blind (BAL) is located less than 7 km outside of Beirut's city centre. Its location is an urbanised village and has often been likened to a quiet and quaint suburb of Beirut. Several old beautiful villas lining the hillside attest to the upper-middle class and diplomats who once considered this area a suburban haven; less than 20 minutes away from Beirut and other major cities, and secluded from their chaos within the folds of valleys. It was during this time, in the late 1950s, that the BAL was built and opened, before semi-low-cost housing buildings sprung up around the city.

The BAL is situated deep in one of the town's corners overlooking a small valley and the adjacent mountains. It is off the beaten path, except for nearby residents, and young men who start their military duty at the neighbouring military training camp. A sign with the name of the school hangs

outside, and at least one of its gates are open for most of the day, but the long wall shielding the school and the guard that stands on duty outside the military camp is not inviting for visitors. The line of vision into the school from the street is very limited, and anyone lingering outside would appear conspicuous to neighbours or any onlookers. The School receives occasional visitors, all of whom the neighbours can see as they drive up to the school. The sudden interest in a car thus appears to be more out of curiosity than concern. If this were exaggerated slightly, the scene would be analogous with gossiping old ladies seated at their windows or balconies to see who walks in and out of a neighbouring pub or betting office.

*Returned to the school, this time arriving in the afternoon. It's much quieter on the road outside, and I notice ladies drinking coffee on the balconies of the buildings facing the school entrance. I seem to be attracting their attention – guess this is not a regular time for cars to be coming into the school, and my presence is that much more apparent as the parking lot is closed now and I had to park right outside the school walls. (Field Notes, 16/Oct/ 2001: 17)*

At ground level from the street, the only view of the school is provided through the wide main gate, which opens onto an asphalt strip where the students spend their break times. All the other buildings in the school are hidden from sight, either by the outside wall, by trees or by each other.

The BAL seems to sit geographically and socially on the fringe of its neighbouring environment. Due to its location on the hillside, there are no other angles that allow the idle observation of its activities from the outside. Whether deliberately or otherwise, it stands apart from its surroundings. The location, and perhaps the uncustomary nature of being a 'special school for the blind', no doubt contribute to the habits of the neighbours who take note of any visitors to the school, and perhaps even weave their own accounts of what goes on there. The neighbouring environment has few links to the School. A couple of the resident members of the staff at BAL have struck up friendships with one or two of the neighbours and they occasionally exchange visits. The older students are allowed to leave the school grounds in the afternoon to buy items

from the nearby grocery store. Other than that, there are practically no other opportunities for the neighbourhood to link with the School, and it thus remains on the outskirts of the surrounding environment.

### ***The Physical Setting Inside the School***

On first sight the school playgrounds, cafeterias and administrative offices are similar to other regular schools in the region. Moments later, however, you realise that you have just entered a small, tightly-knit setting; almost like a little village. Staff and teachers take long looks at you as they pass and make you realise that you are a stranger,, and though they will not ask you your reasons for being there directly, you know that the investigations have been launched (Field Notes, 25/Jan/01: Pg 15). Similar to the curiosity of the neighbours outside the school, one is imbued with the sense of being an intruder into a private space.

In contrast, the students' reactions are mostly of disinterest. You find out later that the students have become quite accustomed to visitors – individual donors who come to survey where their commemorative plaque will be displayed, school students on a field trip to visit “the blind children” in their special school, and university student interns majoring in special education, to name a few (Field Notes, 13/Jan/01: Pg 4). Though the children run their own investigations as to the nature of their visitor, they are selective about this process, and do so only if the visitor will be returning more than once. In the meantime, they emerge on to the playground – or “asphalt strip” as they call it – to go about their regular recess activities.

In a similar way to many other schools, the first point of contact as you enter is with the administrative offices and the open playground. Walking through the school one moves from one area of restricted entry to the next, with the classrooms situated in the remotest part of the ground

floor. First-time visitors who have come to attend one of the school's performances, however, will have the opportunity to walk through all these corridors that eventually lead to the auditorium (see Figures 5.1 & 5.2). The increasing sense of privacy from one corridor to the next is no different than that of any school that takes measures to protect class teaching from any outside distractions. Similarly, the reverse direction, from the classrooms outwards towards the front gates, indicates the levels of restricted entry to students, with the remotest area for them being the administrative offices.

During school hours, all floors other than the ground floor remain off-limits to all students without permission from staff or supervision. Their main circles of movement remain between the classrooms and the outdoor playgrounds. One level of restricted movement differentiates between the residential and the educational aspects of the grounds. Even the TV room becomes an extension of the teacher's lounge during the day-time, and is consequently off limits to students except when accompanied into the space for academic or disciplinary purposes. During the day, the grounds are transformed into a pure school setting with limitations on permitted access for students and staff.

However, the BAL, as with all total institutions, is 'a social hybrid, part residential community, part formal organisation' (Goffman 1961):12). Whereas the formal structure of the school appears to emphasise standard distinctions between staff and students, as part of the hierarchy of authority, it is the residential life at the school, which involves the larger part of the school population, that provides insights into its characteristics as a total institution.

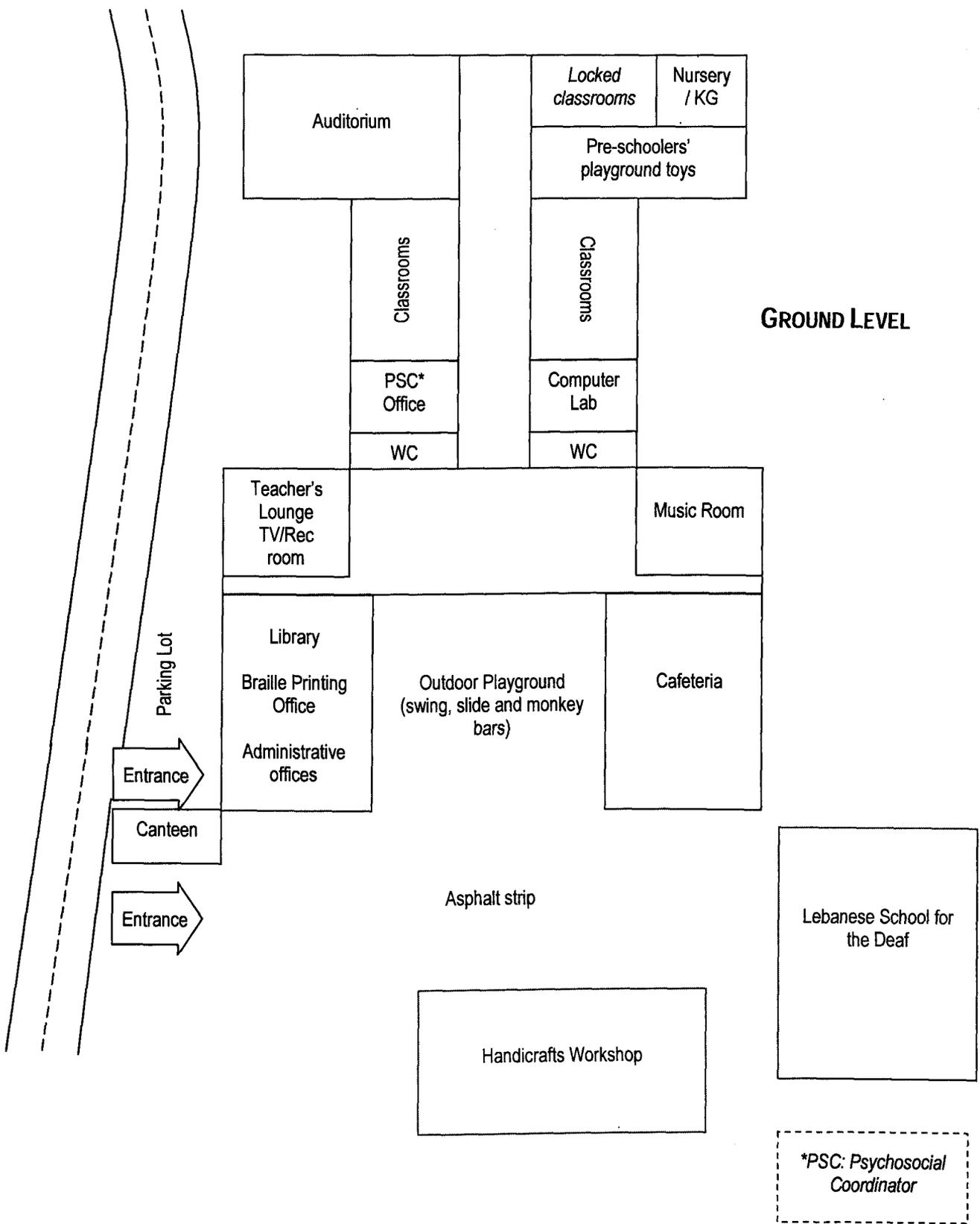
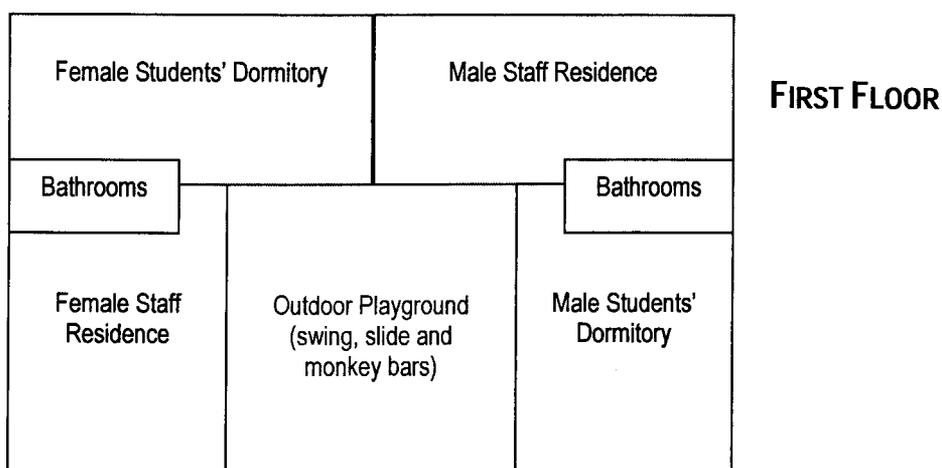


Figure 5.1: Map of the School Ground Level



**Figure 5.2: Map of the School First Floor**

This analysis of the physical space inside the school signifies two main issues that are relevant to our discussion of exclusion versus inclusion – that of privacy, and locus of motion. In a setting that fosters exclusion, individuals are not seen as such but as groups to be regimented in an order that allows for the greatest perceived efficiency of movement and performance, in line with the overall implicit goals of the organisation. On the other hand, an inclusive setting is more likely to allow choices and spaces for individual, and often private, activity within the learning objectives of individual developmental or educational plans.

As mentioned, the children are supervised throughout the school day. At the end of the school day, students who are boarders then go through scheduled sessions of outdoor break, study time, indoor break, dinner and TV time. During this time, the administrative offices, library and other such rooms are locked up for the night, and the children have access to the areas that correspond to each of the afternoon sessions – that is, the outdoor playground, classrooms, dormitories, cafeteria and TV room respectively. Though they are not strictly supervised during these sessions, they are reprimanded for being in the wrong place, and the scheduled times are signaled by ringing bells that are strictly adhered to. Similar to other total institutions, 'persons are moved in

blocks, (so that) they can be supervised by personnel whose chief activity is not guidance or periodic inspection ... but rather surveillance – a seeing to it that everyone does what he has been clearly told is required of him, under conditions where one person's infraction is likely to stand out in relief against the visible, constantly examined compliance of others.' (Goffman 1961): 7). This raises issues of control, as well as privacy.

The issue of privacy surfaced when the researcher was trying to organize a time and place for group work with the children and for individual interviews. For the group work, we were first placed in the TV room during the indoor break session, but that became an inconvenience to others – mostly staff – who wanted to watch television at that time. After some negotiation, we were allowed to use the library which was normally locked during this time, but those privileges were withdrawn when the person responsible for the library found glue on the table where we were sticking pasta shells to cardboard paper, and decided that we had created too much of a mess to be allowed in there again. With all outdoor spaces quickly attracting an inquisitive and disruptive audience, we returned to the TV room and at times to the classrooms, though the students clearly voiced their desire not to be in the classrooms. The classrooms, however, were our only option when the individual interviews were conducted as they provided the only private space that would not inconvenience anyone. The dormitories, were also quite public being one long, large open space divided down the middle by cupboards, and then broken up by dividing walls, creating three to four spaces at each side. Each of these spaces contained six to eight beds lined up face to face against the walls.

Other restrictions that faced us in finding a common space that could be used for group work also brought to light the delineations of the physical space in terms of gender, age, and role in the school. To illustrate, even if we had been granted access into the dormitories, this would have immediately excluded the boys or the girls in the group as one was not allowed into the other's dormitories under any circumstances. Furthermore, though some spaces were assigned as

common to all, such as the TV room, there were hierarchies between resident staff versus students, the handicrafts workshop employees versus students and older students versus younger students. This meant that the younger students rarely obtained easy access to these common spaces. Other available spaces, such as the library or the cafeteria, were considered areas for very specific activities and, as such, were not open to other functions without much persuasion and under specific conditions. This may also be due to these spaces being out of the line of easy surveillance. Wolfe & Rivlin argue that 'once long corridors exist, the free movement of children is further curtailed. Going somewhere distant and out of view leads to the suspicion of problem behaviour.' (Wolfe and Rivlin 1987):104)

Within this description, the issues of privacy and locus of motion become intertwined as they both reflect a measure of control exercised over the children within the physical space of the school. This perceptibly comes to the surface on occasions when the children feel they have moved out of these circles. During one group work session, when we were not able to use the library or the TV room, we found the room to the pre-school indoor playground equipment open and used that space instead. The children, boys and girls, rushed to play with the equipment – though it was a smaller scale than that available to them in the outdoor playground – and upon realizing that they were too far from the dormitories to be heard by the supervisors, they were squealing and screeching as they played. (Field Notes, 13/Nov/2001, Pg 22) The children were never observed to play so enthusiastically, if at all, with the equipment in the outdoor playground, as if that area, which is under easy public surveillance by adult staff, had a different function or required different behaviour. 'Children learn that the overriding purpose of daily settings is functional – there are places to prepare for schooling, places to learn ... - and these purposes prescribe the range of appropriate behaviour in that place.' (Wolfe and Rivlin 1987):107)

Wolfe & Rivlin argue that 'life in an institution, whether it is partial or total, is public. The concepts of publicness and privacy taught in these settings serve the purpose of the institution rather than

aiding the development of the child.' (Wolfe and Rivlin 1987):104) The relevance of looking into privacy, and the locus of motion and control when examining the exclusive or inclusive ethos of a physical environment has to do with how the embedded geographical layers of restricted movement, relate to exclusion, and the issue of individuality. An inclusive ethos asserts that the main focus should be on the individual and his or her needs, capacities and potential. It also builds on the individual's participation. The descriptions listed in this section illustrate that the children's use of the physical space is regulated en masse and that no spaces have been provided to allow for their own personal solitude, or for their uninhibited expression or participation. In terms of participation, this points to a lack of choices for the children in terms of the use of physical space. Treating the children as a homogeneous group also conflicts with recognizing their individuality and their individual needs.

Protection may be the main rationale behind these regulations and measures of control, as this school for the blind is built on the edge of a hill. Goffman (1961) would also argue that this control was related more to fear of liability rather than protection. Additionally, the constant surveillance and lack of privacy for children reflects the staff's 'clinical gaze', the institution's approach to maintaining control and surveillance, 'the often unstated goals of institutions' (Wolfe and Rivlin 1987):105). This, in turn, is connected to the administrators' perceptions of children and of disability that will be analysed further in the next section.

## B. The Social Space

The 'social space' here refers to where the children spend their time while at BAL. It includes both the space that is officially made available to them and that which the children negotiate within these rules. In describing physical spaces in the previous section, the available social spaces were referred to. However, in discussing social spaces, the rest of the school population and their role in defining these social spaces also need to be taken into account in more detail.

As a boarding school, BAL is transformed from a school into residences at the end of the school day. Whereas the three centres that exist on the same grounds; the BAL, the handicrafts workshop and the School for the Deaf; do not interact during the school day, the populations converge on shared territory in the afternoon. That is to say that they are now allowed to share some of the wider public spaces, such as the outdoor playground (or 'asphalt strip'), but they do not necessarily join each other in any activities, with a clear natural separation between the population that is visually impaired and that which is hearing impaired. The students from the two schools are only ever observed to cross paths during meal times at the cafeteria, and are then assigned separate tables. A few of the teenage boys attending the School for the Deaf may occasionally play basketball on the hoops at the edge of the asphalt strip, one would not otherwise meet with any of the students with hearing impairment while visiting the BAL, and could quite easily not realise that there was another residential school at the downward-sloping edge of the visible grounds outlined in Figure 5.1.

The population at BAL is a little over 100 people, including students, teachers, administration and support staff. The BAL runs the handicrafts workshop where visually impaired personnel work – some of whom are BAL alumni – mainly weaving raffia..

Classes run from Nursery to 7<sup>th</sup> Grade, plus a class for girls over 18 who had not previously been to school, with an average of 6 students per classroom. Older students who attend public high schools return to BAL at the end of the school day. The non-student population is made up of teachers, a Braille-printing office staffed by two people, kitchen staff, two drivers, a psychosocial coordinator, an accountant, the Director and her assistant. They are joined by a number of visually impaired adults who are employed part-time or full-time, who take turns running the telephones, assisting in the Braille office, overseeing the library, teaching some students Braille, maintaining school equipment, running errands, and looking after the younger students. Almost half of the non-student population resides in the school, as do most of the personnel of the handicrafts workshop. Though the residential staff consists mostly of females, with the exception of two male teachers, employees from the handicrafts workshop are all male.

The BAL population during the day is quite different from the one that remains there in residence in the afternoon. Soon after the final school bell is sounded, the small parking lot empties out as the cars leave, carrying with them most of the full-time teachers, and close to 25% of the students. The school is suddenly quiet as office doors are locked for the day and boarding students rush up to their dormitories, if only to symbolically signal the end of their school day. Shortly afterwards, the buses return with the older students who go to public schools, and in an hour, personnel from the handicrafts workshop join their bunk-mates in the dormitories (Field Notes, 25/Jan/01: Pg 11).

### ***Negotiating Space***

This influx of the residential population of BAL shifts the age distribution upwards, and the end of the school day provides renewed access to the dormitories and the TV room, thus changing both the physical and the social space.

The schedule of a typical day at BAL was recounted to me by one of the students, and confirmed by another. Interestingly, it was volunteered by the student as her helpful feedback when, upon being asked what I was doing at BAL, I responded that I wanted to learn how they spent their days. The schedule was as follows:

06:30	Wake up
07:15	Breakfast
07:45	Get ready for classes
08:00	Classes start
10:00	Half hour recess
10:30	Classes resume
12:45	half hour lunch break (till 13:15)
13:15	Classes resume
14:30	Indoor break (end of school day)
16:00	Outdoor Break
16:30	Study time
17:45	Break
18:15	Dinner* ( <i>*The older students have dinner after the younger students</i> )
19:30	Study time
20:30	TV time
21:00	Bed time

(Field Notes, 18/Jan/2001, Pg 5)

At the 'indoor break' time, all of the students go up to the dormitories, if only for a short while. The boys can be seen re-emerging onto the playground with toys or snacks, while the girls choose to remain indoors for the duration of the break. During the warm weather, most of the evening BAL population can be found outdoors – the staff sitting and chatting on the side benches while male and female students walked around the asphalt strip arm-in-arm. In the meantime, the boys, and the under-12 population of the school is mainly male, can be seen running around or playing in the corners of the asphalt area. During the winter, very few of the students go outside except for the 'outdoor break', when they are not allowed to remain in the dormitories, and are then confined to the open corridors connecting the TV room, classes and cafeteria entrance. When it rains, they quickly negotiate their way into the warmth of the TV room. This not only requires negotiation with the supervisors because they are supposed to be outdoors, but also entails persuading the staff

who would normally be in the TV room at this time to allow them in (Field Notes, 25/Jan/2001, Pg 15).

The dormitory supervisors, and their deputies, are female staff members who have different roles as teachers or administrators during the day. While indoors (in the dormitories), the students are regularly monitored by the dormitory supervisors, who scold them if they are too loud or too messy. In addition, due to the existing design of the dormitory area, much of what is said in any of the compartments can be heard in all of the others. Not to mention that if they are sitting together too quietly, the supervisor would also be tempted to come in and inspect what they are up to (Field Notes, 25/Jan/2001, Pg 14).

In contrast, the outdoor area affords the students a lower level of monitoring and supervision. In the outdoor space, the supervisors usually just sit on the benches on the periphery, or sit by their window on the first floor, and are pleased that everything is under control if all the children in their charge can be seen from where they sit. This becomes a preferable situation for the children who can now play freely in a larger area, and who can share their thoughts without being unknowingly overheard by others. This might explain why some of the quieter students can be found in avid discussion when walking arm-in-arm with two or more of their friends in the outdoors area. Additionally, as all groups walking together are deep in conversation, there are lower chances of eavesdropping, and lower chances of being overtly teased as other groups would intervene. (Field Notes, 24/Oct/2001, Pg 20).

The outdoor space is also a shared space where the boys and girls can walk together. Moreover, they now have more choices of companions, whether boys or girls, now that the 'evening' BAL population has joined them.

*As the bell was about to ring for the outdoors break, Josette came up and asked me if I was going to walk with her or with the rest of the girls.*

*I did not understand this and asked "aren't you all walking together?"  
"No", replied Suha, "she walks with the workers" (from the handicrafts workshop)*

*I said that I would walk with her this time and with the other girls the next time.  
To which her arm was promptly provided for me to hold her and lead her to the lower grounds. At the door, we met Niveen (who attends a high school outside of BAL during the day), whom Josette introduced to me, and who took her other arm.*

*Just as we arrived downstairs, two other guys arrived who promptly hooked on to the girls, these were the 'workers'. This appeared perfectly planned, and routine. Josette again introduced me to the boys as the good gracious hostess.*

*(Field Notes, 25/Jan/2001, Pg 14)*

*Ghina (who is integrated into a high school during the day) has candidly expressed that one of the things that she prefers about BAL than her home neighbourhood is that she is able to mix with males when living at BAL.*

*(Field Notes, March 2003: Pg 30)*

Both excerpts from the data indicate how the students have capitalised on the shared social space to socialise with members of the opposite sex, and with older students who spend time outside the BAL grounds during the day. The outdoor courtyard becomes not only a shared, less supervised social space, but it also becomes a link to events and news outside of the BAL. Mingling with members of the opposite sex was also an advantage presented to them at the School which would not have been possible in their home environments.

The shifts mentioned above are mainly related to the influx of the returning boarders and the departure of students who do not reside at BAL. Older students can be seen walking around with younger students, or with the younger teachers, or with some of the non-teaching staff at BAL who share their dormitories or perform with them in the BAL choir or band. In this sense, the shared outdoor space in the afternoons contributes to equalising some of the relationships or statuses that are dominant in the daytime. The younger students are more likely to have daytime companions who have left the school in the afternoon, and may be walking around alone, and possibly become the target of play by some of the other groups who might, for example, start a game of tag and make the solitary child 'it'.

*I was trying to catch up with my group and listen to their conversation, but Tony (nursery) who was walking about alone spotted me and was keeping up a conversation. I had him walking with us for a while, although they were moving too fast for him, and I felt unsure about bringing him into this group, where I was myself a guest.*

*Then Maroun (Gr. 2) found me and also held on.*

*(Field Notes, 25/Jan/2001, Pg 14)*

*Before they came to talk to me, Riyad, Adel (both low vision) and Maroun (blind) were playing in the courtyard. A game of tag where the boys with low vision were trying to catch an unsuspecting Maroun.*

*(Field Notes, 17/Oct/2001, Pg. 17)*

Reflecting on these findings with the description of the physical space in the previous section, it appears that the students have negotiated a sense of privacy and expression in what would at first appear to be the least private area on the school grounds: the outdoor courtyard. Not only is this space less supervised than the dormitories, classrooms, TV room and cafeteria, but it is also one of the few shared spaces by the whole population at BAL which becomes open to the non-student population after the school day is over. This afternoon social space provides channels for socialising between those of different ages and gender as well as the transmission of news from outside the school.

The social space is also gendered. The girls were never observed to be openly playing or taking part in any 'fun' activity in the outdoors courtyard. This contrasts with the gleeful games they did engage in with the boys whilst in the relatively closed setting of our group work. They continued to maintain what is considered proper behaviour for young ladies in the more open, public spaces. It is also quite possible that they do this in order to detract any attention from them, and thus gain that margin of freedom in spending time with the older boys or the teachers.

The physical boundaries that have been drawn within the built environment at BAL indicate the school's emphasis on control and surveillance, the value placed on obedience, and the delineation of functions as per the perceived needs of this group of students. The regimentation of time and

use of space teaches the children that 'life is a series of planned and timed events defining human needs rather than responding to them' (Wolfe and Rivlin 1987):107)

The process in which the students negotiate these spaces, as well as other boundaries at BAL, for actions outside the directive order, is directly linked to the formal / informal and manifest / latent ways of expressing authority and power at the school, as the following sections will illustrate.

## **Part II – Mechanisms, Structures and Strategies of Authority & Power among Staff and Students**

### **A. Organisation of Authority & Power – Formal**

An analysis of the formal framework of authority that is adopted by any institution sheds light on several issues that are pertinent to the topics under examination in this chapter. The formal framework is the overt and public system that defines the institution in terms of its priorities, principles and values. Consequently, it assigns a higher degree of authority to posts and individuals who are considered effective partners in pushing through the institution's goals and principles. It is this framework that imparts these posts, individuals and the target groups with channels to participate in the decision-making mechanism.

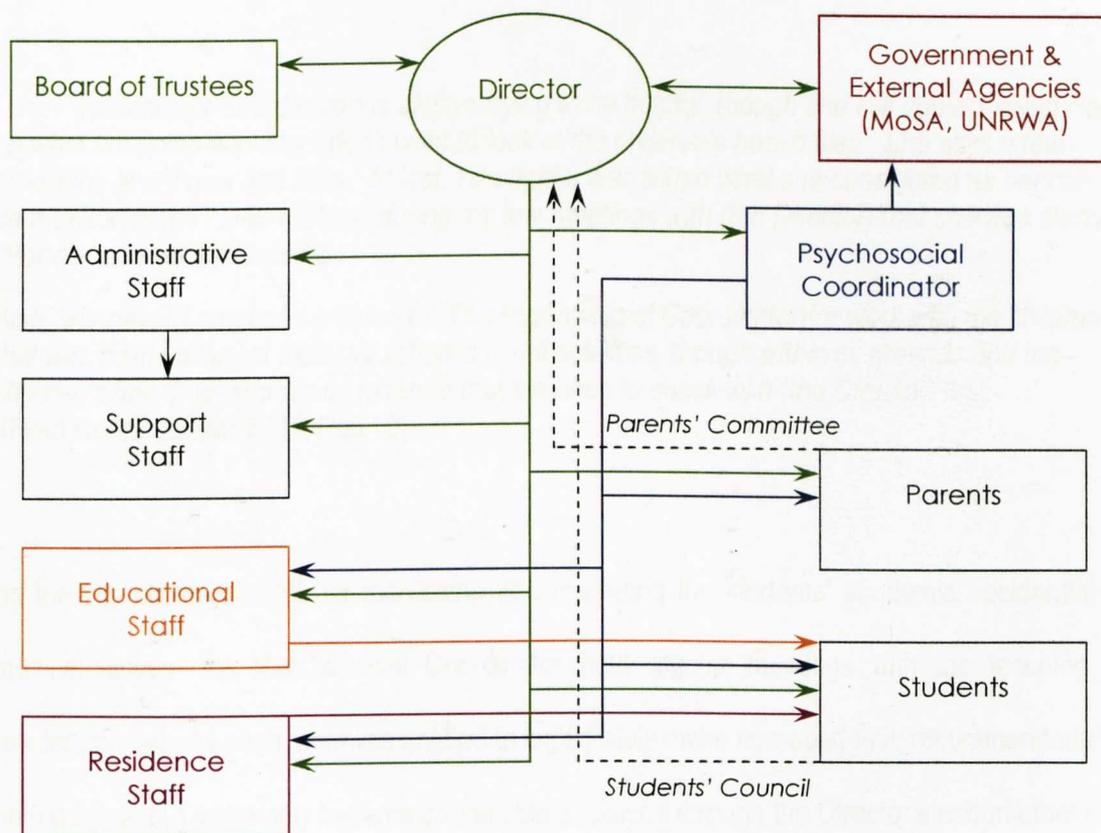
Therefore, the formal framework of authority is being analysed here to explore the values of BAL vis-à-vis the exclusive or inclusive ethos it adopts, both in terms of the values that it prioritises as well as the mechanisms to foster the involvement of stakeholders – teachers, staff, parents and students – in its decision making.

#### ***The Administration & Staff***

The hierarchy at the school is quite clear-cut and traditional. It follows a pyramid, with the Director of the school at the top, who is also the director of the handicrafts workshop as well as the adjacent School for the Deaf. The rest of the pyramid follows the rules of job position and seniority and, at times, personnel with visual impairment fall a little lower on that job scale. The Psychosocial Coordinator holds a “second-in-command” position due to her role in coordinating and mediating all student issues with the teachers, residence supervisors, administration and parents. The students are at the very bottom of this pyramid, and they would assert that they themselves are sorted in terms of age. This is discussed further in the following sections.

Though, technically, an organisation chart for the staff exists at the school, this is rarely referred to, and any decisions that need to be taken concerning the students, teachers, staff, buildings and equipment usually involve the Director, as illustrated in the Chart 1 below. This micromanagement may be, in part, due to the small size of the institution, and in part due to the accepted prevailing management method.

Figure 5.3 is not designed to imbue any particular significance to the lengths of the arrows or the order of the different groups. Its main objective is to illustrate the pattern of decision making between these groups. Arrows that are drawn in one direction are meant to indicate status as well as the direction in which interaction can be formally initiated. They also naturally point to existing, though unequal, pathways between the groups.



**Fig. 5.3: Organisational Chart at BAL**

As the flowchart illustrates, the Director carries an official responsibility to lead and manage all of the groups, and is the sole decision-maker in administrative matters. The Board of Trustees is a registered organisation that was established mainly to fundraise for the School. The position of trustee is mostly an honorary one, and those invited to the Board are considered key persons that would assist in raising the profile, and income, of the School. Though the Board may technically wield some decision making power, that remains mostly with the Director, who is a member of the Board and who is the Board's only contact regarding the school's progress and needs.

The Director may delegate authority to the Psychosocial Coordinator at her discretion, but decisions are usually approved by the Director before they are taken. Additionally, though the Psychosocial Coordinator fronts several group or individual meetings, the Director is always informed of their content. This emerged during any of my meetings with the Director, be it regarding my own work there or incidents with any of the teachers and students.

*(The Psychosocial Coordinator) is always trying to be helpful, though she still doesn't seem clear on what I'm doing and why I don't want to look at the children's health files. She asks a few questions every now and then. At first, I thought it was within what she considered as her role to be monitoring me I later realised during my few meetings with (the Director) that she was always informed of what I was doing.*

*Also, whenever I proposed an idea to (The Psychosocial Coordinator) for work with the children that was a little different than the school's usual activities, though within its grounds and the children's free time, she would reiterate that we need to check with (the Director) first. (Field Notes, 25/Jan/2001, Pgs 10).*

As the person responsible for monitoring and mediating the students' academic, residential and medical issues, the Psychosocial Coordinator held regular meetings with the teaching and residence staff. As such, she was entitled to legitimately make non-academic recommendations to both groups, but these only became irreversible decisions through the Director's endorsement.

Academic decisions, related to the schedule, curriculum, or examinations, were made in consultation with the teaching staff, but were ultimately taken by the Director. In this respect, the Director also took on the role of the Head of the teaching staff, which is not uncommon for a school with so few teachers.

As demonstrated in Figure 5.3, the only legitimate authority that teachers and residence staff possessed was over the students. They were entrusted to make any day-to-day decisions within their role with the students. They may be able to affect other decisions through their access to the Director and the Psychosocial Coordinator during their regular meetings. Moreover, any formal dealings with the parents were conducted in conjunction with and through the psychosocial coordinator and possibly the Director. The administrative and support staff did not have any legitimate links to the students, and any matters related to any of the other groups – teaching staff, residence staff, parents and students – were carried out through the Director or Psychosocial Coordinator.

The dashed lines emanating from the boxes for parents and students in Figure 5.3 represent pathways to the Director that are provided by the Student Council and the Parents' Committees, each of which can legitimately influence central decision-making.

The students annually elected a Student Council of 15 members, which embodied the only formal representation of authority for the student body. However, only students over 14 years of age were eligible to nominate themselves for a seat on the council, and students under the age of 10 were not eligible to vote, rendering the council not representative of a large part of the student population. Though the Student Council would bring demands to the administration, its main function over the years had been to raise funds and organise social activities for the school body.

The only other regulated channel that students in the higher grades possessed to express their concerns to the administration was through a weekly, one-hour “adaptation class” that was scheduled for Grades 5, 6, and 7. These were run by the Director herself, and were closed sessions to which no other member of the staff or parent were allowed to attend. An alumnus provided some insight into the nature of these classes, generally noting that they were usually for the director to do “whatever she wanted to do in that hour” (Jamil, 2005 interview). He could not recall that it was “such an important hour”.

*Jamil (2005): The issues that she brought up sometimes had to do with the blind, and sometimes not. For example, I remember one adaptation class she came in to discuss communism, and that it was the movement that was destroying the system.*

*Sometimes we would discuss our problems at the school.*

*I remember this one time she came in and discussed with us how the blind person becomes introduced to persons of the opposite sex. We liked her when she did that because we felt that she knew we were doing something, not that she blindly believed that there was an order at the school that was being implemented.*

*I don't remember many of the topics, they didn't really stay with me. I don't even recall that it was such an important hour.*

*What was different about it was that if we were going to see the Director in her office, we could only speak of things that were appropriate to take up with the administration, but during this hour, it was a more relaxed approach.*

These sessions provided a more informal channel to the Director, but she exercised a considerably high level of control on their content, and it may be said that she used them as opportunities for introducing her own agendas.

The parents were elected on to the Parents' Committee, which brought all the parents together for a meeting at least once or twice a year. This committee had the legitimate right to raise school issues with the administration, but did not wield any decision-making power. The meetings were usually poorly attended, and the aims of the meetings had, in recent years, focused on raising funds to help finance the children's stage performances/ productions, and in contributing to the

tuition fees and expenses of some students. The Director and Psychosocial Coordinator attended these meetings, and usually facilitated them (Field Notes, 19/Jan/2001, Pg 7). The Parents' Committee communicated directly with the Director and Psychosocial Coordinator, but not the teaching staff. In addition to the parents' informal visits to the school when picking up their children at the end of the day or for the weekend, the psychosocial coordinator scheduled annual home visits to all the parents with the university student interns. These home visits covered issues concerning the student's health, behaviour and academic performance. The psychosocial coordinator admitted, however, that some of the children's homes that were located over several hours' drive away in the North or West of the country were sometimes not visited.

The only groups who answered solely to the Director were the administrative and support staff and the Psychosocial Coordinator. The work of the administrative and support staff had an immediate bearing on financial issues; in terms of reporting on funding, time and cost efficiency. The Psychosocial Coordinator was largely the Director's assistant, and was given an authoritative role with some of the groups, but mainly reinforced the Director's authority.. Notably, academic issues related to the students were not shared with the Psychosocial Coordinator.

Academic issues remained out of bounds to anyone other than the Director for she was, the only one with the authority to address academic issues with the teaching staff and students. Both the teaching and residential staff had authority over the students, but the teachers possessed a slightly higher status because they were responsible for the students' academic education. Furthermore, the parents also held the teaching staff in high regard. As indicated by Figure 5.3, however, and evidenced by conversations in the teacher's room during recess, this did not entitle a teacher to initiate an action with a parent without first receiving clearance from the Director.

*(Field Notes, 24/Jan/2001, Pg 8)*

*They (the teachers) invite me for coffee and cookies in their Break room. (The Director) joins them for a cup and though they seem mostly happy to see her, they're clearly trying to be "on their best*

*behaviour". They talk about some of the students, forget who asked first, and they kept deferring to her any time they made a suggestion, about the child or involving the parents.*

As for channels of active participation, or initiating action, it appears within this formal framework that the three groups with the fewest mechanism for participation were the support staff, parents, and students, in decreasing order. The fact that their opportunities for participating were so limited could possibly be related to the fact that they were not perceived as possessing the expertise required to take these decisions. Where the support staff were concerned, their limited participation could have been linked to their roles being of a non-academic nature and several degrees of separation away from the students.

*When the bus-driver came in, and then one of the kitchen staff, they only managed a quick gesture with the children (lifting them up, tickling them) before (the Supervisor) made her presence clearly known and they silently went on their way. (Field Notes, 18/Jan/2001, Pg 6)*

*The tall girl who runs errands was chasing after Leila to get her to walk back to the TV room and tell her off for walking off. She stopped in her tracks when she saw a teacher approach and just turned back. (Field Notes, 25/Jan/2001, Pg 15)*

However there was resistance to these hierarchies of control and this was expressed through informal mechanisms by the students. This is reminiscent of Foucauldian ideas of power and resistance to the clinical gaze of surveillance (Foucault 1973), however, the dynamics of power and influence amongst the students reflected in many ways the dominant values of the institution they were living within and those of the wider Lebanese society.

## **B. Informal Organisation of Authority & Power among the Students**

Whereas the formal organisational structure of authority reflected the priorities and values that supported the surveillance and control of the students and were openly declared by the

administration of the school, the informal organisation shed light on the perceptions and social constructions of all the different groups co-existing at the school, their social dynamics and power relations and forms of resistance. Social status was negotiated by attaching value to elements such as age, gender, impairment, academic achievement, talent, economics and expertise. This was empowering to some and conversely disempowering to their peers and others. These values were revealed by observing how the students resisted some of the formal lines of authority in order to have some power and influence within the school.

In analysing the exercise of power, the issue of participation is highlighted, which, as a main parameter of an inclusive setting, reflects on the school's exclusive or inclusive ethos. Save the Children Alliance, a network that is renowned as a leading organisation on children's participation, defines it as a process that "... is about influencing decision-making and achieving change. Children's participation is an informed and willing involvement of all children, including those who are differently-abled and those at risk, in any matter concerning them either directly or indirectly. Children's participation is a value that cuts across all programmes and takes place in all arenas – from homes to government, from local to international levels" (Save the Children 2003): 2). There are, naturally, different forms and levels of participation, which may relate to any one of the parameters listed in this definition, but ultimately refer to the extent to which children are able to influence decision making and bring about change. This definition reflects several waves of developing Arnstein's ladder of citizen participation into Roger Hart's ladder of children's participation (Pridmore 1998), and shifting from these linear concepts to recognise the hybrid of these levels serving the goal of promoting participating as an inalienable right. Inclusive settings would aim to create as many systematic opportunities as possible for children to participate, as well as for parents, teaching staff, and all others involved in the children's lives at the school.

The formal organisation of authority described in the previous section groups the students all together in one category, and they are assigned a ranking at the bottom of the hierarchy. Through

analysis of the data, it became apparent that the students had defined their own informal status hierarchy amongst themselves, by utilising attributes relating to gender, age, and disability. At the higher end were the boys versus the girls, the older students versus the younger students, and students with low vision were higher up relative to those who were severely visually impaired. These were the characteristics that defined differential status amongst themselves and between them and the adults. In other words, an older boy with low-vision was informally afforded more status than a young severely visually impaired girl. That is to say that he would have been considered more dependable and influential both in word and deed. Though this was an ascribed status resulting from their attributes, adults also recognised parameters relating to achievements and abilities, thus introducing achieved status among the children as well. Consequently, children who were high academic achievers, musically talented or precocious achieved higher status than their peers. It is of note that attributes and elements through which the children attained ascribed or achieved status greatly reflect attitudes and social perceptions existing in society at large.

### ***Age & Gender***

The students were formally divided into two groups through classes, study time and meal schedules, with the cut off point being 4<sup>th</sup> grade. The group of children studied in depth, between 7 – 12 years of age, fell into this younger group. The fifteen children that fell into this smaller group consisted of only three girls and a top-heavy distribution of ages in the 7-12 year age range. Only two children from the nursery class were boarders, three were in 2<sup>nd</sup> grade, four were in 3<sup>rd</sup> grade, and the remaining six were in 4<sup>th</sup> grade. Lebanese society is patriarchal, discriminates in favour of males and bestows more respect and responsibility to older children. It was thus natural to investigate whether these attitudes were also present at BAL, both among the children and the adults. Data from the participant observation and group work with the children were analysed for incidents or behaviour that reflected these attitudes.

Among the children, a constant theme that emerged was the taunting and bullying of the young children.

*It got a little out of hand at one point (especially when they turned off the light and scared the wits out of poor Tony) and I had to take control again and calm them down.*  
(Field Notes, 13/Nov/2001, Pg 22)

This excerpt is just an example of a scene that would occur during any of the group sessions, when the older children would hound the younger ones by teasing them or hiding their colouring pencils or the like. The older children's sense of superiority surfaced on a few other occasions. During the very first group work session with the children, I had brought in play-dough and colouring pencils for the children to start working with. All of the children wanted to use the play-dough, and as there was not enough for everyone, one of the older children immediately suggested that the older children should have it first as the younger ones will not know what to do with it (Field Notes, 23/Oct/2001, Pg 18). This attitude towards the younger children was one of the reasons that led me to break up the children participating in the group work sessions into two subgroups, with the main criterion being age.

On another occasion, when playing "animals of the jungle" with the boys out on the asphalt, the older boys chose to be the powerful animals.

*It was strange how the children responded to playing a game of "animals of the jungle". It was before I was due to leave the school and the boys were just hanging around outside, and we started playing the game – the idea was that they had to choose an animal and imitate its sound. The boys took it further to imitate the actions and strength as well... What was interesting was how the older boys refused to be the weaker animals, even when one of the younger boys had beaten them to choosing a strong animal. They would either ignore the younger boy's call and take on the stronger animal themselves, or would refuse to play, or would ignore the rules of the game and still pretend to be hunting an animal that was supposed to be stronger than them.*  
(Field Notes, Pgs 23-24)

The choices in the game reflected the social relations and social differences between them, and made it difficult for an older boy to accept being the 'weaker animal' to a younger boy.

This uneven dynamic between older and younger children is not uncommon in any day or boarding school. It becomes interesting, however, if it is also reinforced by the adults at the school, as some students implied.

*Ayman: "(I hate the way) the teachers blame us for everything that goes wrong. It happens less now that there are classes younger than us.*

*I asked the guys (Grade 5) how things were going and if they were getting into any trouble. Walid jokingly replied "Us? We wouldn't get into any trouble ... we'll just busy the teachers with the younger kids!" he grinned. (Field Notes, 25/Jan/2001: Pg. 15)*

The adults were seen as reinforcing differences related to age and the children correspondingly valued age and used it as a means for being heard and challenging or influencing decisions.

A limitation of the data was that the 7 – 12 years age group only contained three girls. The older girls had also been attending the school for a few years and had learned to hold their own with the boys. It would follow from this discussion on the ascribed status of age that an older girl should be able to assert some power over a younger boy. When the opposite is true, however, that would imply that gender has superseded age in allotting power. Although the girls' behaviour was generally reserved and did not attract the boys' attention, examining the data revealed a few incidents where gender superseded age. One such example occurred between an older girl and a younger boy, both of whom were severely visually impaired, and were high academic achievers. T

*In today's session, Kamal kept telling Samia off for not calling me "Miss" despite everything I said about how it didn't matter. Samia resisted for a while and continued to call me by my name as she had before, and as I had asked them all to do, but by the end of the hour, she was worn down, and either avoided using my name or finally succumbed and called me "Miss". (Field Notes, 1/Nov/2001: Pg. 22)*

Such incidents indicated that boys of any age felt that they could instruct the girls, on how to behave. The boy in question possessed other elements that may have allowed him to exert pressure on his peers, but he was never observed to be doing so to older or bigger boys.

This mirrors discriminatory practices in society, which, though not necessarily supported by the adults at BAL, was not being challenged by them either.

### ***Visual Impairment***

Societal attitudes towards disabled persons have been outlined in previous chapters. This section draws on those images and perceptions of disabled persons as weak or incapable of being active participants in society. These attitudes were observed not only between individuals at BAL who did not have a visual impairment towards those who did, but among the children with visual impairment as well.

There is a saying in Arabic, which when roughly translated says “A one-eyed person, among the blind, is king”. A value was placed on some sight being better than none at all among the student population at BAL in various ways. Students with low-vision frequently took on the role of being the teacher’s helper, either on their own initiative or upon the teacher’s request. Students with low-vision took on the task of leading new or younger students who were severely visually impaired to the bathroom or to their classroom, or anywhere else around the school

*The students with low vision immediately lead the severely visually impaired students to the room when the bell rings.*  
(Field Notes, 18/Jan/2001, Pg 5).

In one gym class, a student with low vision automatically took on the role as the coach's helper, refereeing a game of 'blindfolded handball' and making sure that nobody was cheating by looking through their blindfolds.

*Lubna (who has low vision and wears glasses) is automatically coach's helper and takes over the whistle as well. She makes sure no one is cheating.*  
(Field Notes, 18/Jan/2001, Pg 6).

In these settings, students with low vision saw themselves, and were seen by adults, as being more capable and responsible than their peers with severe visual impairment.

Amongst the children themselves, the children with low-vision were not necessarily helpful towards their peers with severe visual impairment and exhibited belittling behaviour towards them. This type of behaviour was not specific to any one child, it emanated from practically all the boys with low vision.

*Before they came to talk to me, Riyad, Adel (both low vision) and Maroun (blind) were playing in the courtyard. A game of tag where the low vision boys were trying to catch a reluctant Maroun.*  
(Field Notes, 17/Oct/2001, Pg 17)

*However, there was always something going on where the low-vision boys were teasing and tormenting one of the blind boys.*  
*They would sneak up on him to poke him in the head or slap his neck.*  
*They would sneak up to grab him into a head lock.*  
*They would empty out one of the trash cans and sneak up to put it on his head.*  
*It was also often between the older boys and the younger ones (where the former have low vision), or between the older boys – those who have low vision and those who are blind.*  
(Field Notes, Pg 24)

This is the kind of bullying behaviour that would normally be observed in a school yard from children who were in fact stronger or bigger than the other children, seeking out opportunities to prove it. In the episodes described above, however, the target of the bullying behaviour was not necessarily physically weaker or smaller, but was always a child with severe visual impairment. It cannot be said that this type of behaviour is condoned by the school in any way, but as with most

bullying behaviour in schools, it frequently went unnoticed by the adults. When adults were around to intervene, the bullying children were appropriately reprimanded, for their behaviour and for picking on someone 'weaker' than themselves. The pertinent issue here is the higher status and level of power exercised by the children with increased levels of vision.

This dynamic between the children with low vision and those who were severely visually impaired was also mirrored among the adults at the school. Aside from the four visually impaired teachers at BAL, most of the visually impaired staff carried out minor support staff roles. They worked as telephone operators, substituted for absent teachers, provided additional lessons in Braille, or sat with the youngest children who did not have a study session in the afternoon. Some of them actually did not have clear tasks, but they ran odd jobs or errands to justify their residence at the school. It might be coincidental that the staff with visual impairment occupied these roles, which can be perceived as less important than those taken on by the rest of the staff, but this feeds into the socially predominant discriminatory perceptions of people with disabilities. Especially as the same is not true for any of the employees at BAL who was not visually impaired, all of whom had clearly outlined tasks and work schedules. It would be fair to assume that these perceptions impacted on the dynamics between the children as well.

### ***Academic Achievement and Musical Talent***

The importance assigned to academic achievement at BAL emerged earlier when examining the formal framework of authority at the school. Putting such emphasis on academic achievement is to be expected of an institution that considers education as its primary role. At BAL, the students' school achievement included both academic and musical skills. As musical performance has, for years, been considered a suitable and respectable vocation for people with visual impairment, the students at BAL were taught how to play a musical instrument as soon as they entered the school.

This was followed up by the director herself who attended weekly recitals by the students and offered her praise or critique of their performance. Excelling in academic work and music reflected well on the school, and staff, and was a source of pride. Academic scores as well as musical talent of the children were rated highly by the staff, and influenced the child's standing with the others.

Amongst each other, the children did not necessarily recognise this as a sufficient reason for their colleagues to carry additional power or status. It did, however, influence dynamics of support that these students received from the adults. The staff did not necessarily recognise their part in reinforcing the hierarchy of relations among children achieved through ascribed status of gender, age or disability, but they were active in supporting achieved status of academic or musical achievement, which naturally bred favouritism.

In the age group of children under study, one such child exemplified this behaviour. He was a young, diminutive child with severe visual impairment, but with good academic standing and abundant musical talent. Yola and Aida could be frequently heard talking about Kamal and his latest achievements – Aida (proudly) “*You could see him, he was just so upset when he couldn't remember the right answer*”, Yola: “*He would have gotten the highest academic score in the school if they took into account the nights he spends practising with the adult music band*” – not to mention illustrating favourable treatment to him in the playground and in class, by constantly calling on him to answer, and, at times, almost directing the teaching only to him.

*It is one of the last periods of the day and I walk into the class while they are in the middle of a quiz-game type activity testing some of the general issues that they had been learning. The class was split into two teams, the teacher was reading out some questions (mostly history) and the first child to raise his hand got to respond and possibly win a point for his team. The children all seemed to be having fun, except that it was quickly apparent that they were losing interest as most of them did not get to respond all that often. Kamal kept raising his hand first insisting that he knew the answer, and the teacher would wait until he figured it out, or even give him clues to get it right. It was clear that he did know most of the answers by himself, and that he was the quickest to raise his hand, but the game soon became a one-on-one quiz with him being the only one taking part. I found it interesting that the teacher did not think of adjusting the rules in the slightest*

*to encourage the others to try to find the answers and take part in the game as well. Not even when some of the started wandering away to the window to see if there was anything going on outside.*

(Field Notes, 18/Jan/2001: Pg 7)

This inclination of the staff towards favouritism was apparent during the participant observation and confirmed by alumni.

*Jamil: "During that first week, there was a lot of favouritism towards me because I was new (...) the favouritism increased when I was seen as smart."*

This achieved status far surpassed parameters of ascribed status, and children who lacked status in the latter were able to compensate for it with the former, and frequently proved it by exerting this power.

When the group work sessions were broken up into two sub-groups according to age, one of the younger children who performed well both academically and musically, objected and insisted that he be with the older group. This was supported by his closest friend who was in the older group, though the others did not particularly get along with him and had, in fact, been the ones to suggest that they be split into two groups because they felt the younger ones were disturbing their work. Despite this, they did not object, and it became apparent through other incidents that they did not see the point of standing up to him knowing that he could probably persuade me, either directly or through the other adults, to submit to his demand in the end (Field notes, 24/Oct/2001: Pg. 22).

The other children were not necessarily intimidated into not expressing their frustration about these issues, but they did not feel that doing so would affect any change. Another incident arose during the fieldwork, when the children had requested that the recess before the last study period in the evening be made shorter so that they could finish and leave earlier. As this affected the time of my group work with the children, it was explained to me by the supervisor that this was

better because it was getting cold in the evening and the children were getting sleepy. In a paired interview with two children, they explained to me, with irritation, that it was Kamal, a child with high academic and musical status, who claimed that he was getting cold and sleepy and had asked the study teacher to make the request to the dormitory supervisor. The rest of the children had not been consulted, and those with friends in the higher grades, who had different study and break schedules, may have wanted the recess time to remain the same so that they could still have common time to spend with their friends. *“And now, we just sit and wait”* (Ref: interview with Samia and Munira)

This was, in many ways, the most openly displayed form of discrimination by the adults, and it was accepted to some extent by the children, perhaps because it was considered justified. It would not be unreasonable for a school to value educational achievement, but this takes on an additional dimension in a boarding school when this sort of favouritism affects decisions in the residential realm as well. The student population was effectively socially stratified not only by age and gender, but also by vision, academic grades and musical skills. As illustrated here, this played a role in the power relations among the students who boarded at the school.

### ***Socio- Economic Status***

Most of the students at BAL came from families of low economic status. A child with slightly better economic standing was not treated any differently by the adults, nor did it automatically impinge on the relationship with the other children. However, in sharing his or her snacks with the others, or in allowing bunkmates to steal his or her money (Jamil's interview), the child was ensuring their cooperation and support in confrontations with other students, or possibly even with the adult staff.

Students of particularly low economic status received the attention of the staff, but this did not positively influence the student's standing with others. This attention was sympathetic and charitable, with staff members covertly offering the children candy or buying them clothes (Yola's interview). In the spirit of 'zakāt' or 'sadaqa' and similar teachings in all religions indigenous to Lebanon, lies a religious-social practice of anonymous charitable action towards those less fortunate than oneself, which is usually translated into monetary donations or, more predominantly, in-kind donations consisting of items of clothing or food. This is the socially acceptable manner of handling charitable actions in order to allow the recipient to save face. Consequently, this connection to the staff did not carry the same effect as it did for children with high academic achievement because it was not a public action, and disempowered the children when it was noticed. Notwithstanding that, as most students were from low economic households, this was not a prominent criterion by which staff could justify any favourable treatment, it did, however, break the ice on more than one occasion with students that the teachers would nonchalantly call trouble children.

*Though he drives many of the adults crazy, they all seem to have a soft spot for him. One teacher gave Yola some money to buy him a jacket as he had outgrown the one he had. He was otherwise always in torn, tattered or smaller clothes. And he never had any candy left over with Yola, or allowance, or the like. (Mazen's interview notes)*

Though this was not one of the major forces affecting social dynamics between the students, it was also not one to be ignored. The impact of their economic situation on the children and their dynamics was more potently influential on the decision-making dynamics and relationship between the parents and the administration, as will be illustrated later on in this chapter.

As indicated earlier, many of these elements of the informal power structure mirrored values held in society that also worked to distinguish some over others. Consequently, the data was revisited to search for any other possible elements present in societal attitudes that may carry weight among the students at the school. Namely, issues such as sectarianism and refugee status, which are openly dominant in society, but had not appeared as clearly in the primary analysis of the data.

The children openly talked about their own religious rituals, whether celebrations or fasting or the like, but none of the interviews or observations hinted at these sectarian differences playing a role in the child's power status. In fact, a lack of knowledge of other religions was apparent among the children making it difficult for them to attach additional perceived status to one over the other.

*Ayman and Ahmad are working away at their playdough...*

*"Miss, do you fast (Ramadan)?"*

*- No I don't.*

*"But isn't that shameful? You're big and everything" (jokingly)*

*- But I'm not Muslim*

*"How can that be, you're name is Maha and that's a Muslim name"*

*- No, that's an Arabic name*

*"But my sister is Maha."*

*"Well, how about Hiba?"*

*- Hiba is also just an Arabic name.*

*"But Ahmad is a Muslim name"*

*- True, but Mahmood is not. Christians also name their children Mahmood.*

*"Goodness"*

*(Field Notes, 24/Oct/2001: Pg 20)*

In another instance, it was made clear to me by one of the older students that the administration frowned upon talking about religion.

*Afrah asks me what my religion is, and I say I'm neither.*

*She doesn't get it, but refrains from continuing, and tells me that the school has a strict policy about discussing religion or politics – it is simply not allowed.*

*(Field Notes, 18/Jan/2001: Pg 6)*

All of this naturally does not mean that the children did not share their stories on celebrations or gifts or practices related to their respective religious rituals, and though the group of children under study were possibly old enough to discriminate against each other based on their religious sects, there was no room for this to affect informal status as it was actively rejected by the administration and adults at the school.

As for refugee status, the student list indicated that in the whole student population there were only 4 Palestinian refugee children, and only one of them fell into the children's group under study in this research. For the entire duration of the field work, there was only one observed incident where this child was taunted because of his refugee status as a Palestinian. However, the two children involved in this incident were at diametric opposite positions of the achieved status spectrum, which was the more likely source of informal power being exercised. Interviews with an alumnus who is a Palestinian refugee confirm that refugee status/ ethnic discrimination was not exercised at BAL, though she was quick to accuse other organisations of that sort of discrimination.

*Do you feel that there was racism at BAL?*

*- No, there was no racism there.*

*(The students were all equally trouble makers)... I was really powerful in the dorms and I didn't really care about the rules, and I was having a great time.*

*(Alumnus Ruba's interview)*

As such, the more pertinent parameters of the informal power structure among the students remained those that were outlined for ascribed status (age, gender, visual impairment, SES) and achieved status (academic or musical achievement).

The dimensions of the informal hierarchies and status differences amongst the children was quite strong. Children who, within this web of ascribed and achieved status, were at the bottom of the ladder were not able to break through despite whatever other talents or attributes they may have

possessed. For example, a young, severely visually impaired boy who had a talent for fixing things and putting them together, and who also owned the only ball available to the children during their playtime, remained on the lower rungs of the status ladder and was constantly teased and picked on.

*Maroun also has a knack for fixing things.*

*After he would have tired of trying to put something together, he would push it my way. On one such instance, it was a small construction plastic boat that he had won at the centre of a chocolate egg. While putting it together, he had broken off one of the connecting notches, so I returned it to him improperly assembled. A few minutes later, he showed it to me again, completed. Reassured that there wasn't a fixture he wasn't managing to connect properly, he had compensated for the broken notch by biting the piece through to its correct place. The boat did not lose its shape at all, he had found an alternative way to fix it.*

(Maroun's interview)

This is the same severely visually impaired child who was consistently observed as being taunted and teased by other boys with low-vision. Another boy who was a natural athlete, but who performed poorly academically and musically, was constantly reprimanded by the staff for being hyperactive because he was always trying out one athletic feat after the other during his breaks (Notes on Mazen). Though both these boys were talented in different ways, these were not criteria that were consensually accepted by the children or adults as worthy of admiration or respect.

### ***The Effects of Informal Power Relations among Students on Coping & Decision***

#### ***Making***

This analysis of the informal hierarchies of stratification among the students sheds light on how the students coped with problems or concerns that they faced, and how they were able to negotiate channels for their participation in decisions taken by the administration or by groups who held a

higher rank in the formal authority structures. Through these hierarchies, they expressed resistance and agency within the constraints of the formal structures.

The only direct formal channel that the students had that could affect decision making was through the Students' Council. As this mainly represented students above the age of 14, it did not play a part in the lives of the younger students under study. Resistance had to be accomplished by capitalising on or manoeuvring through the hierarchies of status and influence amongst the children. This was reflected in the way they dealt with each other and in how they went about seeking attention, advice or assistance. In other words, in coping with problems and affecting change.

Owing to the small size of the student population at BAL, the standing of some children was magnified, and there were not many options for making friends. Those who had higher ascribed or achieved status became popular, which provided them with a support network of friends. Alternatively, the interviews with the children revealed that those who were of low status, did not possess such a support network and tended to depend on themselves in times of crisis, often just passively retreating.

*Field Notes, 24/Jan/01: Pg 8:*

*During recess - The children are teasing each other, and Kamal chants at Ahmad (a derogatory slogan). Ahmad quietly walks away trying to avoid hearing the chant.*

*What would you do if someone was bothering you?*

*Adel: I would just hit them...*

*Kinan: I would create some chaos, then I would go away somewhere to play so as to forget and not be disturbed.*

*Maroun: I would get mad, wish that bad things happen to them, and I would just leave them alone.*

These children ranked low in status and did not recognise any options other than taking matters into their own hands – mostly to express displeasure – and finally retreating. This contrasted with

the responses of the children of higher status, all of whom were more apt to rely on their friends or on adults for support.

*What would you do if someone was bothering you?*

*Samia: I would talk to Munira about it*

*Munira: If it is really bad, I would speak to (the director).*

*Kamal: I would try to talk to the administration, to the director.*

*Riyad: Well, we fight about things, but then, things have to calm down... (implying that it was the friends' duties to help calm it down) ... (if things are a bit too much or get out of hand) We talk to whoever is closest, either (the director) or (the dormitory supervisor). But (the director) helps more*

These children who carry some weight in the informal power dynamics have not only identified a support network among their friends, but from their vantage point, they also recognise who wields the ultimate formal authority and under what circumstances to negotiate or demand assistance. Children with high status felt empowered to express their concerns or complaints, and influenced decisions concerning their schedule or participation in activities.

In light of the students' routine and regimented daily schedule after the school day was over, it was interesting to note that children who were higher up on the informal power scale were also the only ones who were able to identify some aspects of their life at BAL when they felt autonomous. In their interviews, they were able to name some phenomena that they liked at the school where the others could not think of any. They were the ones who had found ways to affect decisions among adults, or had been able to get away with doing things that the others dared not try. These adventures sometimes made them more interesting to the adults and other children, and further increased their status.

*"Shall we go some place where none of them will find us?"*

*The he took me to a gate between the classrooms which opened into and untended garden behind the school. There was a small paved strip and some stairs, where we sat down to do the interview. He did not say much about what was around us and let me do most of the describing, and he seemed very proud that he was able to bring me to this place that I had not been to before. When I told (the dormitory supervisor) about this later, she just shrugged it off with a smile. (Riyad's interview)*

Riyad was a boy with low vision and a good academic record. He was perceived by the adults as being capable and responsible enough to safely bend the rules, or geographic boundaries. Others of similar or equivalent standing could likewise get away with mischief that, if executed by other children of lower standing, would normally lead to them being reprimanded, as was frequently observed as a response to Mazen's antics on the playground (Field Notes, Pg. 23). They were successfully deploying strategies of resistance.

### **C. Control, Participation & Resistance of Parents**

Parents formally participated in decisions at BAL, through the Parents Committee as shown in Figure 5.3. They were subject to other informal mechanisms that reinforced the authority of the school administration. The data analysis revealed that parental socio-economic status together with the ways they respected the expertise of the administration and staff working with their visually impaired children, contributed to creating a dependency on the administration that deterred parents from challenging decisions that it made or expressing resistance..

The relationship between the administration at BAL and the parents is not, in fact, equivalent to that for parents of children attending regular schools. The parents sought out BAL due to the fact that it was a 'special school for blind children', and was perceived as specialised in handling their children. They also did not recognise any other alternatives for providing their children with an education.

All the parents who were interviewed recounted how, when their child's visual impairment was confirmed by diagnosis, they had received little social support in terms of guidance or advice regarding how to work with their child. The only guidance they did receive was to refer them to

BAL. The majority of the parents had found BAL through word of mouth, and were grateful to the school primarily because it provided an educational opportunity that was not available to their children within their local surroundings, and because it offered a form of professional guidance and support that they longed for.

Ayman's mother:

*It wasn't easy for me to send him. But Ayman was having a tough time at home, he wasn't accepting his predicament. He was always angry or nervous. It all changed when he went to (BAL), he calmed down considerably.*

They viewed BAL as an expert institution which they counted on to work with their children. This was expertise that they felt that neither they nor neighbouring schools possessed, which heightened their attachment to and dependence on BAL, as indicated in their own words.

*Ahmad's interview: They came by a month ago and offered to have the children included in UNRWA schools around here. They said that the schools were prepared to take in blind students. But I refused – nothing will be like the education at (BAL). I see the difference between my children and the students that go to UNRWA schools. When we have foreign visitors, Ghina can speak to them in English ... we all know what UNRWA schools are like.*

Ayman's mother's views on BAL education: *I wouldn't remove my child from (BAL). The educational level is much better there than anything available around here.*

In addition to the academic superiority that the parents attach to BAL, they also recognise its influence in caring for their children residentially as well. When speaking of BAL, the parents ascribed some of their children's mannerisms to being in BAL.

*Ahmad's father: It's different at (BAL) than if they were going to school here. You can see the difference. They're disciplined to be polite, their social interactions are different (better). There's a blind boy here in the neighbourhood who was kicked out of (BAL), and you see him just standing at the corner swearing at people. Very rude. I don't want my children to be like that.*

*Ayman's mother: He is very neat and very organized, and that is thanks to (BAL).*

*Riyad's father: (the director) really sets things right. We are really happy about the school in general, we haven't had any trouble ever since we sent Riyad there.*

The parents attributed higher, more sophisticated values to the environment at BAL than in their own environments.

The parents view the school administration as being more competent and qualified to make decisions concerning their children. The same applies to the educational and residential staff who were able to handle their children when they themselves and their neighbourhood schools could not. This deterred them from challenging the administration's authority, and limited their participation at the school. Not only did they fail to see the need to question decisions being made at BAL, they were also aware of the limited alternatives accessible to them for educating their children.

### ***Socio Economic Status***

As previously mentioned, all the children came from families of low socio-economic backgrounds. As students of the BAL, their tuition and boarding was fully funded by social service agencies: Lebanese children were supported by the Ministry of Social Affairs, and Palestinian refugee children were supported by UNRWA. Additional expenses for medical treatment or the like were sometimes covered by these two agencies or by other charitable organisations.

*Ayman's mother: But we would be very supportive of any such movement for the rights of people with disabilities, and for ensuring medical insurance and the like. They (department working on Law 220 at MoSA) issued Ayman a "disability card", but I haven't used it yet. Ayman is sponsored by "Bayt Al Zakāt" (Muslim charity organizations, which sponsors orphans among others), which took care of him when he got his seizures.*

The payment system for Lebanese and Palestinian refugees differs slightly. UNRWA sponsors the handful of Palestinian refugee children at the school, and negotiates terms of reimbursement with

the parents, but this is usually only a percentage of the total sum. This is corroborated by one of the parents, who was the father of three students at BAL:

*Ahmad's father: At first, they (UNRWA) let me pay 20%, and then brought it down to 10% (for the girls), and then UNRWA took care of (the youngest boy).*

UNRWA also follows up the children's files with the school administration, where discussions take place regarding the child's progress and potential to move out of BAL to a vocational centre or an UNRWA inclusive school, at which point UNRWA is relieved from covering their expenses, as education at the UNRWA school was free (Personal Communication with the Disability Advisor at UNRWA, 2003).

As for the Lebanese children, most of the expenses are funded by the Ministry of Social Affairs (MoSA), especially for children who are boarders, with no repayment stipulated from the parents. Additionally, the administration at BAL oversees the children's paperwork with MoSA, and the list that it submits annually of recommended children to be registered and sponsored is rarely challenged by MoSA. In fact, one of the responsibilities of the Psychosocial Coordinator is to act as the liaison with the Ministry, on behalf of the school where expenses related to the school are concerned, and sometimes on behalf of the parents and children for issues related to the 'Disability Card' procedures.

*Field Notes, Parent's Meeting, 19/Jan/01: Pg 7:*

*(The psychosocial coordinator) reminded (the parents) ... as well as paperwork with the MoSA. She reminded them all that, because their child is a disability card holder, they can ask to be exempted from the municipality taxes, as well as customs and some Electricity and Water fees. She informed them that she would heading down to the MoSA office in the following two weeks if any of them had their paperwork ready and wanted her to submit it.*

In providing this assistance, the administration encouraged a dependence on it by the parents who neither had the time, nor the know-how to carry out such procedures at MoSA, nor, at times, the access to the Ministry due to the distances they would need to travel to arrive at the central

processing unit at MoSA in Beirut. Furthermore, as their financial contribution was minimal, and the decision of sponsorship depended on the administration's recommendations, the parents no longer carried the weight of a 'client', as would be the case in a typical 'patron-client' relationship, in their dealings with the school. If anything, parents would probably be inclined to remain on good terms with the school in the hope that this would continue to produce favourable recommendations for sponsorship.

The students had often preferred staying at BAL, as outlined in the following chapter, but an interview with an alumnus revealed that the students' submission to administrative decisions was, in part, related to their understanding that they were financially dependent on BAL. He recounted an incident *"when the students found out that MoSA was paying for them, they threatened to complain and protest"*, but he quickly remembered that the students generally did not provoke or cause too much trouble because *"they were also scared of being expelled"*. (Jamil's interview)

Not unlike the sentiments of their parents, the students felt grateful to BAL in many ways. Aside from accepting them as students, living there offered more to some students than living at home.

*Jamil: "The other students came from poor families, what were difficult circumstances for me were great for them ... which is why some students didn't want to go home on the weekends."*

To some, the BAL was sophisticated in comparison to the home environment. As mentioned earlier, the parents recognised the advantages, in addition to the education, that the school offered their children. These were advantages that they were not able to provide within their closer community, in terms of polite behaviour and the like, as well as sheltering them from discriminatory social attitudes. They perceived these as improvements in their children's quality of life. Every now and then, this was confirmed to them by the items or opportunities that their children received as students at BAL, which they would not have been able to afford.

Aside from the 'expenses per child' that the BAL received from MoSA and UNRWA, it also raised funds from two other specific sources. A non-governmental organisation was set up by the Director of BAL with the sole function of fundraising for the school. The school also received donations from wealthy individuals, usually for equipment or building construction and renovation, which were commemorated with carefully mounted plaques bearing their names. The BAL also received donations of clothes, books and other items from other schools and organisations.

*I walked into the TV room to find piles of books on the floor. Yola explained to me that they were old versions of textbooks that were donated to BAL by the IC. The teachers were sorting through them to see what could be used in class or in the library and she encouraged me to take any that I wanted.*

(Field Notes, 17/Oct/01: Pg 17)

*In Yola's room later in the evening, in what had become my habit to spend some time with her and Aida after I finish my session, a student from the older classes walked in to ask for help with some of his homework. As Yola introduced me to him, she also asked him how the performance and visit to the Hariri school were. He said that they had done well but was rather annoyed that all they gave them were sweat suits that were all the same size.*

(Field Notes, 1/Nov/01: Pg 21)

The parents learnt of these occurrences from their children, but were also informed by the administration which explained how it obtained these donations. This took place in meetings of the Parents' Committee or in the opening speeches of the Director at any of the school performances, such as the Christmas concert (Field Notes: Pg 1). With the Parents' Committee, and individual parents, falling far behind in their ability to fundraise on a similar scale, the administration retained its economic stability and dominance.. This was another factor in the authoritative, almost paternalistic, relationship between the administration and the parents.

One final issue related to economic factors that restricts the participation of parents at BAL is that of being able to afford the time or the transportation required to be at the school. Parents who do not, in fact, work cannot always afford the transportation from their distant home to the school. Those who do work can rarely leave their jobs to come to the school.

Riyad's father: *We're members of the parents' committee, we contribute whenever we can, but our time is very tight. The school even came to us a while back with an idea for parents to serve 4 hours or days a year at the school, but we really don't have any time to spare for that.*

Ayman's Mother: *Being a single mother and working, I am not able to attend any of the parents' meetings, or go to the school. I have only managed to go once or twice since Ayman went there.*

Several elements in the dynamic between the parents and the administration at BAL were raised here that related to financial issues. In all of these, it was shown that this was an unequal relationship, with the administration possessing a higher level of control. In some instances, such as applying for and following up procedures with social services agencies for sponsorship of tuition and boarding fees, the administration did not only play a pivotal role in the process, but, in its provision of assistance, encouraged a dependency that helped but disempowered the parents. As the school was perceived as offering a better quality of life to the students than the parents could have provided, the parents, and the students, shied away from 'biting the hand that feeds them'.

A school with an inclusive philosophy emphasises the importance of involving parents in their children's school life. Examining the formal organisation of authority and decision making, and hence participation, illustrated that the parents had a direct, collective formal mechanism of influence through the Parents' Committee, as well as informal individual channels through meetings with the Director and Psychosocial Coordinator.

Interviews with parents of children at BAL generally reflected how pleased the parents were with the school, and how highly they thought of it. They viewed the school staff as expert specialists in dealing with their child, and generally felt compelled to agree with decisions either due to their faith in their technical prowess, or because they feared that they had no other alternatives to educate their children. This dependence on the School was for both educational and financial reasons. As all families hailed from low economic backgrounds, several issues related to funding and finances were tightly connected to the administration, where the administration carried more

knowledge, skill, weight and control. This created an imbalanced relationship between the administration and the parents, and discouraged them from not conforming to any decision-making process at the school. Thus, though the school took formal measures to try to involve the parents in different aspects of the school life, these factors were simultaneously contributing to the parents' limited participation.

## **D. Educational Principles at BAL**

Looking into exclusion versus inclusion at BAL would be remiss without an analysis of the educational system there. From an extremist inclusive point of view, BAL would be immediately disqualified as an inclusive setting because its classroom population does not reflect the natural distribution of social parameters (gender, ethnicity, disability, and so on) present in society. However, as explained earlier, the analysis here aims to examine whether the school adopts an exclusive or inclusive ethos in its system. This section thus explores the educational principles adopted by the school administration in the management of the teachers, the students and the curriculum.

The administration at BAL viewed academic education as its primary role, as indicated in the formal organisation of authority and in the favouritism expressed towards children with high academic achievements. It even emphasised that role in its name – where other similar organisations offering educational and boarding services to disabled children called themselves “association” or “centre” or “institution” or the like, it calls itself the “BAL School for the Blind”. The administration similarly felt that formal education was the main concern of the parents as well, as indicated by the director who was preparing me for the home visits by warning me that “*the first thing they’re going to ask you is how their child is doing in school*” (Field Notes, Spring 2002, Pg.

25). It was interesting that none of the parents did, but that will be discussed in more detail in Chapter 6.

The School aimed to cover all the learning objectives listed in the Lebanese curriculum such that the students may enter the official, certified government examinations (at 6<sup>th</sup> Grade and 12<sup>th</sup>/13<sup>th</sup> Grade levels). All textbooks were converted into Braille, and large-print copies of the textbooks were made available to older students with low-vision who did not learn Braille before entering the school.

The students started learning Braille at Nursery level. This was compulsory to both students who have low vision or are severely visually impaired. Staff expressed the view that learning Braille was an added advantage for children with low-vision in the event that their sight deteriorated as they got older.

*Children with low vision are taught Braille as well as being taught to read later on, as I am told by the psychosocial coordinator. "It's better to make sure that they know Braille as well. They gain a language, and they have something to fall back on if their sight deteriorates..."*

(Field Notes, 11/Jan/01: Pg 3)

It is debatable, however, how effective this was as students with low-vision in 4<sup>th</sup> grade and higher were often seen to be bent over their Braille textbooks and reading them rather than feeling them with their fingers.

*"One of the boys with low vision is hunched over so close to his book that it appears as if he is reading Braille with his nose, but it turns out that he is reading it with his eyes." (Field Notes, 25/Jan/01: Pg 10)*

*Riyad's father: "I know! I see him reading it – and not with his fingers – and I just go "what are you doing?""*

Introducing Braille to children with severe visual impairment is considered one of the main steps in early intervention that would prepare them to enlist in a school. However, there are other elements to early intervention programmes for children with visual impairment, such as training for tactile recognition, gross and fine motor skills, and physical space orientation. This is usually executed employing simple tools, toys and material that can usually be found in any pre-school. These were also observed in an integrative pre-school, both in the regular kindergarten classrooms as well as the special class that children with visual impairment attend for part of the day to attend to the skills listed above.

*Here, they are taught the pre-Braille basics. (The teacher) works with them on their muscle tone (motor skills), sense of touch, and Braille basics. They will be learning about Braille this year in time to go to school next year.*

*One activity in these areas: using a peg board to place pegs around shapes that the children are given. The room is full of regular toys that have been brought in for these purposes ... including a toy pedal car.*

*(Field Notes, 11/Oct/2001, Pg. 29)*

These measures were not observed to take place in any of the classes at BAL. Aside from Braille, the students are not taught any other orientation skills. All grades had physical education classes scheduled into their week's programmes, but the students often sat the activities out, or converted them into a time that allowed them to play in the safety of a closed setting, and perhaps in the absence of an audience. They were left to their own devices in learning how to find their way around the school, and the younger children were often discouraged from playing around in the playground for fear that they would hurt themselves. Young children with severe visual impairment usually relied on their peers with low-vision to lead them around or to share in their play.

*Jamil (Alumnus) on his first day at BAL: "I felt quite lost. Nobody told me how to go from the room to the bathroom or the classroom. It was the blind kids who helped me."*

*Yesterday, while the KG/Nursery class was just sitting outside waiting to be taken home, there were no children on the asphalt because they were still in class, and no one was really keeping the young children company and they were just bored, knowing full well that they would have to wait a while before it was time for their parents to pick them up, or for the boarders to go upstairs. So I*

*asked them if they wanted to race each other. I held hands with Yasmina and Leila and would narrate to them the path they were running in a sports announcer style as we pretended to race Tony and Hussein (low vision). The girls were holding onto my hands tightly but were clearly enjoying themselves when Adma came and stopped me, explaining to me softly but sternly that I was not to play with the children in this way – what if somebody fell and hurt themselves? (Field Notes, 18/Jan/01: Pg 6)*

The only teaching aid that was available in any classroom was the Braille textbooks. A couple of tape players, which were shared by all the classes, were occasionally brought in when the lesson was supported by an audiotape. The walls were bare, save for the occasional flat biology poster or the like. The non-tactile nature of the decorations that were hung up during holiday seasons indicated that they might be for the benefit of visitors rather than the students. The children themselves had little art supplies available to them, except where requested for an assignment, and they were not offered any Art lessons. One of the younger students who took part in the group work sessions had been attending BAL for a little over a year, and yet was still visibly unfamiliar with playdough as an item in itself, or with knowing how to handle it.

Field Notes, Pg. 23:

*When she was given playdough, she would roll it with her fingers into little pieces, she would smell it, and would always end up continuing the motion through her hair. It seemed as if she was trying to discover it.*

The older children were familiar with, or were quick to discover, how to use the playdough, but these group work sessions revealed more about how much they have managed to explore mundane items, such as kitchen or bathroom fixtures, and develop a sense of size or scale.

Field Notes, Pg. 23:

*The severely visually impaired children were making things into 3D shapes, but they were totally out of proportion. Some of it barely resembled what they were trying to make. Jaafar would ask me if what he was making looked like the kitchen or bathroom that he was asked to make, and two things were apparent here: he had an idea of what they were supposed to look like and what was inside, but the proportions were off, and he had not before explored what some things looked like, especially things that he could feel if he wanted (such as the bathroom fixtures).*

Sessions or measures to teach the children about non-academic matters were not observed throughout the period of classroom and participant observation conducted at the school, and were not deduced from the children's mannerisms or knowledge. The curriculum that was designed for the students at BAL was purely academic in nature – with minor adaptations – and with a strong emphasis on teaching the students to play a musical instrument.

*When you're sighted, there's a lot that you know or you learn without being taught. (I) would notice that as a difference between (me) and (my) friends at BAL. (I) realized that much of this was not being passed on to them in other ways by the school.*

- Interview with an alumnus who had entered the school at the age of 12 upon becoming visually impaired.

The School, and indeed the Director, made only one formal contribution to the social development of the students: "adaptation" classes that were offered to the last three grades in the School (Grades 5, 6 & 7). This was a non-academic, social preparation weekly session with no one else allowed to attend other than the Director herself. It was not even possible to find out any details about the class from the Psychosocial Coordinator who herself had never attended one of these classes and was not privy to what takes place (Field notes, 10/Jan/01: Pg 2). As the adaptation class was described earlier in this chapter, the alumni who were interviewed could not recall anything striking from these adaptation classes that contributed to their integration into regular high schools or society, but they remembered the class more as a channel to express their concerns directly to the Director. Without access to the class, it is impossible to assess their relevance.

### ***Educational Staff***

The daytime teachers – five of whom were visually impaired, out of which three were alumni of the school – were not trained to teach students with visual impairment. The teachers admitted that

they were not specialised, but claimed that they had attended some courses since coming to work at BAL. Most of these courses were about education in general, but two teachers travelled to participate in a workshop on early intervention and low vision. The teachers all found their way to the BAL by chance or by invitation from the Director.

*From the teachers' group interview:*

*Teacher 1: I used to volunteer at the school, and then was asked to teach full time.*

*Teacher 2: I used to teach at another regular school, but it closed down. (The director) then asked my husband if I was interested in teaching here, so I came.*

*Teacher 3: I used to be a student here, and (the director) saw that I was smart and could help her, so she asked me if I wanted to stay on and teach here.*

*Teacher 4: My sister is blind and I came here with her. She became a student and I got a job.*

*Teacher 5: My friend used to teach her and she got married and left the area, so I applied to teach in her place.*

*Teacher 6: I used to give private lessons to (sighted) students, and volunteer here at the school, and then (the director) asked me if I would like to teach full-time. I told her that I had never taught blind children before, but she suggested that I just try it out, so I did. I didn't know anything about teaching blind children; I learned it all, as did most of us, by trial and error*

The lack of background credentials in education aside, the teachers helped and trained each other on how to run their classes with children with visual impairment. Their level of commitment and interest in teaching is not in question, but the absence of training in active, non-traditional methods of teaching, and the lack of supportive educational aids left them at a disadvantage. It hindered their ability to manage the classroom; their limited skills were often stretched to limits, and, on more than one occasion, they were observed to resort to methods that cannot be considered appropriate for dealing with children with visual impairment.

Field notes, 25/Jan/01: Pg 10:

*Here and in (the other grades) yesterday, the kids are always spending a lot of time trying to find where they are reading while the teacher simply goes on...*

11/Jan/01 – in the Nursery/KG: Pg. 3

*Tony and Hashem had their glasses off at the request of the teacher (both have low vision) – she does this to them to control their movement when they are too hyperactive.*

Field Notes, 13/Jan/01: Pg. 4

*Physical punishment is employed as a threat – it has only been observed in one situation so far as a slap on the face (Grade 2).*

Other incidents that took place during the data collection reflected how little educational and dormitory staff knew about the basics of dealing with persons with visual impairment. This extended from rules of thumb, such as signalling your presence when you enter a room, to creatively identifying alternatives from the 'sighted' world that would allow the children to learn or develop.

Field Notes, 25/Jan/0: Pg. 14 – afternoon visit in the girls' dorms

*She (the dormitory supervisor) had walked into the dorms earlier, and I did not appreciate that she was mouthing a short conversation with me, which the girls would not be able to see. Especially that she didn't say anything important. It seemed as if she did it as her own way to emphasise the girls' visual impairment.*

Field Notes, 24/Oct/01: Pg. 20

*I was sitting outside with Aida (one of the teachers) during one of the students' afternoon breaks. I had just arrived and it was not yet time for my session with the children. Aida had to attend to something else when I was once again mesmerized by the dull routine movement of the older children, boys and girls, arm-in-arm walking round and around in circles on the asphalt. When Aida returned, I just blurted out: "I just want to figure out why they do that – why do they just walk around?" Aida responded: "What else are they going to do?"*

From the teachers' group interview:

*Teacher 6: It is totally different than teaching sighted students. I mean, 90% of what a student gets is from his vision, so the teaching had to be very different. I mean, I would be moving around and gesticulating, but that isn't doing any good. I teach English, and I talk Arabic in class, though I shouldn't, but there was just no other way.*

*Teacher 2: Absolutely different, a sighted child would understand quicker because he/she is using their sight.*

*Individual teacher interview (Mr. Taha): Also, don't forget that the **image** plays a big part, blind children can't keep up with the sighted.*

Additionally, BAL's visually impaired teachers did not have any assistance in class from support staff who were not visually impaired, which presented another disadvantage to the efficacy of their classroom management.

Field Notes, 25/Jan/01: Pg. 10 – Grade 5 English class taught by one of the teachers who is blind: *MF is totally asleep in class today (and the teacher doesn't notice) ... The class made use of audiotapes to have a lesson read out (American accent) ... (yet despite this) ... they are learning about hibernation (which is being mispronounced by everybody) ... "Bears" is being mispronounced as well ("beers").*

Alumnus who now runs a pre-school integrative programme for children with visual impairment: *As a student, I used to cheat the blind teachers all the time! Copying from the students around me, dancing, picking oranges from the tree outside the window, cheating, etc. When I teach, I must have a sighted assistant in the room with me.*

Despite the teachers' limited knowledge and attitudes where some of these issues are concerned, the teachers and students have a friendly and supportive relationship.

*Teacher 6: When I first started teaching here, I was so tensed up and so worried, but the students are the ones who helped me. They would keep cracking jokes... (about their visual impairment)*

*Teacher 7: But I feel that a teacher is the one who can best understand and communicate with the students – they see us more than they see their own parents! Especially as a blind teacher, I have been able to find solutions for many of the children's problems, and more importantly, can communicate that to them.*

*Teacher 6: They sometimes get to have a say about the time of an exam, chapters that are to be on the exam (not all agree), the length of a homework assignment, eating chips (crisps) in class, etc.*

*Teacher 4: They get away with it more than 'normal' students*

The teachers do not only feel that this a regular job for them. In many ways, the school has taken them in much like it has done for the students – there were not many other alternatives available to them. They feel that they have become part of a small community, an emotion no doubt supported by the small size of the population at BAL, and perhaps also by the fact that they work with a 'special' group of students. One of the teachers summed it up when she said *"This isn't like just any other school, we became a family. And (the director) is like a mother."* (Group interview, Teacher 6)

## *Academic Standards*

With all the emphasis that the school administration places on academic achievement, it is, in fact, difficult to assess whether the academic performance at BAL is indeed high as there were no other special schools for children with visual impairment for several years. However, BAL was the first special school to have a student pass the Lebanese Baccalaureate exam (Scientific) in the 70's, with no adaptations or additional time being provided to the student (Ref: Jamil's interview). Students from BAL continue to submit for these official examinations with moderate to good passing results, though many question the standards by which these students' exams are graded, including BAL's staff. The staff shared their thoughts that the grades of the students in the official exams were not accurate or valid, that they were higher than the students deserve, and that the students were being automatically passed.

*"Who knows how well qualified they will be – they are all passed in their government exams (baccalaureate) without the examiners even looking at their papers." (Yola)*

*"They are not doing any favours for the blind students with the formal exams, where we all know that all blind students definitely pass (no matter how they perform on the exam)." (Mr. Taha)*

As previously mentioned, the classes at BAL only go up to Grade 7. At the end of the 6<sup>th</sup> Grade, students are evaluated to assess their ability to be integrated into a public high school for the three remaining years of schooling until the baccalaureate. The administration bases its decision on whether to integrate students into these high schools on the results of the official government exam that they sit at the end of 6<sup>th</sup> Grade. A coordinator is in charge of finding public schools that will accept the BAL students, and the students are aware that their distribution among these schools is then decided by the director.

*Ghina ... attends (a regular school) in Hadath.  
She named five other girls who go to school outside ..., but they attend three separate schools ....  
When I asked how they were distributed in this way, Ghina said that not all schools can absorb too many blind students, and Josette contributed that (the director) decides where they go.  
(Field Notes, 25/Jan/01: Pg. 12)*

If the students' results are not up to par, they continue their classes at BAL. The last grade at the school, however, is 7<sup>th</sup> Grade, after which the students stay in the class an additional year until they are integrated into public high schools, or they are left to seek vocational training at BAL or elsewhere, or simply drop out.

During the period of data collection, one or two instances cast some doubt as to the academic level of the students who had managed to be integrated into a regular school. On the days of the group work session with the children in the evening, one of the supervisors would ask if I could assist one or two of these students in their assignments. In one such instance, it was to assist a student while she completed her exam in English Comprehension. The exams are brought to BAL where the Braille Office produces them in Braille and the students type out their responses on a regular typewriter. The evening staff does not take any additional supervision measures, often just placing the student in a study session classroom to complete the work.

Field Notes, Pg 25:

*Maya sat in one of the classrooms (where the older children were also doing their homework), unsupervised, and I was asked to explain the text and the questions to her. It was a comprehension exam.*

*I was struck by two things here:*

*First, that she was left to handle an exam as she would her own homework, unsupervised and in a crowded room with other students who are at her same academic level (if not higher).*

*Second, that she understood very little of the text or the questions, and I had to leave because any additional explanation from me would be to simply give her the answers. Did the other staff help in that way so she expected me to do the same?*

*There was also no apparent time limit on the exam, and I wondered if the other students in the school would take her grade seriously knowing that she took the exam to do it at home.*

Upon once making a comment to one of the supervisors as to this weak level of the students, she merely shrugged it off with a sympathetic “*what can you expect?*” (Field Notes, Pg 25). This reflected the general attitude of the teachers who would naturally hope for high achievement among their students, but had mostly low expectations. When the teachers were asked what

career prospects they felt were available to their students, they struggled with their responses, many of them not saying anything at all.

*Teacher 6: I only see them working as phone operators  
(Which others – mainly the blind teachers – disagreed with)  
Whatever they think of doing, they must go to university. There is no other way they can compete  
for the same jobs as sighted graduates.*

When one of the teachers with visual impairment suggested that there will now be more job opportunities as everything becomes computerised, one or two teachers concurred that perhaps the students could go into computing (Teacher's Group Interview). However, they still implied how difficult this would be for the students in terms of achieving the type of academic scores that would enable them to be admitted into a college or university.

*Teacher 6: And all of this is assuming that they will graduate from here.  
I mean, we work our hearts out with some of these students to get ahead in any subject (but nothing...)*

As can be seen, *Teacher 6* was of the more outspoken teachers in the interview, but upon hearing this and other statements, the rest of the teachers either nodded with approval or, as in the case with the newer teachers, froze in a state of slight shock as these were not issues that were to be verbalised to outsiders such as the interviewer.

Alumni interviews cast some doubt as to their perceived value of the education that they received at BAL, especially after they graduated and returned home or sought work opportunities.

*“(BAL) prepared me to go to university and study Mathematics – which I then dropped because I realised that I couldn't do anything with it, not teach or anything. It told others not to go to university ... (and) would refer them to the handicrafts workshop or train them to work as phone operators. There is one girl who spent 12 years at (BAL) and (she feels) she can't do anything, not even make a sandwich.” (Jamil's interview)*

This may not be the case for all alumni, but the sentiment is supported by others who were interviewed who proceeded to re-educate themselves after leaving BAL (Ref: Abed's, Ruba's interviews), and is reflected in the number of alumni who return to work or to live at BAL. Some have even argued that BAL's move towards integrating older students into regular schooling was fuelled purely by financial reasons.

*Jamil's interview: Even in recent years, with all its attempts to include students in the higher grades, it's just because they did the math and realize that they could no longer afford to open up classes for a handful of students at those levels. It was just more cost effective for them to place the students in regular schools, but they insist that they continue to live at the school.*

Academic learning was the main perceived purpose of BAL. Though the teachers expressed mixed expectations of the students' abilities to achieve or go on to better things, their main aim was to continue with their efforts to prepare the children academically, as this was the only means they saw for the children to be able to measure up to persons without visual impairment.

## **E. Conclusions**

The analysis in this chapter addressed research questions 1 and 2. Addressing the first research question focused on to what extent the *BAL School* has managed to adopt an inclusive ethos and practices in its organisation and management. Research question 2 on the existence of mechanisms through which voices of the children are heard has been addressed through the analysis of the structured and unstructured opportunities for the children and their parents to participate and voice their opinions.

The findings have shown that BAL was operating as a 'total institution', with integrative measures appearing tokenistic, at best. Within such a system, opportunities for participation, where they

exist, were limited and were delineated within the School's perception of worth, which was mainly by academic achievement or musicianship. Furthermore, the Administration had achieved an 'expert' position among parents by corroborating notions of technical expertise in educating, treating, rearing and financially supporting the children's development. This completely stifled resistance from the parents, and by proxy, the children, and nurtured a disempowering dependence on the School in all these matters. The data clearly showed that the Director's authority was recognised by all, especially the parents and students, who sought out her assistance as the individual who possessed the most legitimate authority to issue final decisions.

In relation to the immediate surrounding environment, the school population was generally cocooned within the school grounds. Though some teachers expressed their opinions that much awareness raising needed to take place in society in order to change current attitudes towards persons with visual impairment, they did not recognise the inhibitory role to this process that the school was playing. The issue was not only that the school is a 'special school for the blind', which on its own merit falls into predominant attitudes that disabled children should be taught in a separate setting, but the school's physical environment was also closed off, thus preventing the community circles around it to learn anything about them. Similarly, during the long periods that the boarding students spent at the school, they received very little exposure to the social world outside their school walls. From a physical space point of view, this setting translated 'segregation' into 'isolation'. Within this environment, surveillance was constant, in the classroom, cafeteria, playground and dormitories. The children were monitored within a regimented time-space schedule, and this surveillance extended to their homes through visits of the Psychosocial Coordinator and the folders that she maintained for each child, as well as to the regular schools that some of the older students were integrated into. Whereas the 'total institution' nature of the time-space schedule did not necessarily affect non-residential students in the same way, they were included in home visits and the system of monitoring folders.

The principles that have been adopted by the school administration and staff are reflected in all its official protocols, relating to educational and residential guidelines, and in the informal organisation of authority and power propagated by the children and with the parents. The administration presented the school as a special, expert institution in a manner similar to medical rehabilitation centres. Its efforts were focused on rehabilitating the children academically and musically as a means towards compensating for their disability. The curriculum and modules of teaching did not include any adaptations that would make the child comfortable with their impairment, not even in adequately training the teaching staff, but rather urged the child to perform within a non-adapted educational environment. As a result the school was promoting the normalisation of the disability by encouraging the children to overcome it as a means of being able to fit back into society. As re-integration into society was cited as the school's main goal, analysing its exclusive versus inclusive ethos gave some indication as to how effective these measures were for re-integration.

With its educational approach and the control of social space, the administration treated the student population as a homogeneous group, with the inference being that they were similar because they shared the same disability. The only distinction that the administration made among the students was for those who had excelled academically or musically. These attitudes were not challenged by the students.

The school administration had recreated a regular school and sought to train the children to manage themselves within it. This not only applied to the formal curriculum and system, but to the attitudes adopted regarding age, gender, and disability as well. The children among themselves employed these parameters in their perceptions of who was more powerful or dominant, and these were aligned with the discriminatory attitudes prevailing in society. The most striking was the distinction that was made between children with low-vision and those who were severely visually impaired, and the role that the adults played in supporting it by giving tasks to the children with low-vision that were not related to their age or academic achievement – factors that teachers

usually use when choosing a helper – but solely on the fact that they had low-vision. This reinforced the perception of the severely visually impaired children that their impairment was disabling them.

The teachers maintained low expectations of what the students could achieve after BAL, and alumni claimed that BAL did not prepare them for anything that benefited them later. As the alumni interviews illustrated, whether they succeeded academically at BAL or not, the education that was provided to them proved useless in later years, with a number of them re-educating themselves in profitable occupations.

The school administration therefore primarily subscribed to the medical model of disability and a non-inclusive curriculum. The children did not have legitimate, representative arenas in which to participate, and their informal participation was hinged on their placement within a discriminatory set of parameters. Furthermore, it lay the burden of achievement on the children alone, and offered no alternatives to build on the children's strengths if they were not academically or musically gifted.

The parents came to the school with a medical definition of their children's impairments in line with the formal diagnosis. This understanding did not seem to change as they moved their children to another expert institution; one that they considered qualified to make decisions for them regarding the children. This discouraged their involvement in any school issues, which they felt they were ill-equipped to advise on, and fed into their dependence on the school that was not only educating a child that nobody else knew how to teach, but was also assisting them in obtaining sponsorship and funding.

From a Foucauldian perspective, it can be deduced that an institution such as BAL was established to 'reform' disabled children into acceptable, productive members of society. Aside

from the elements of segregation and normalisation illustrated by the findings, the strength with which control is exercised throughout the School's practice with children and parents led to imbalanced power relations, so that decisions by the School were rarely challenged. There was no room left for resistance, and whatever the children managed within the school grounds remained quite restricted to small transient initiatives within informal circles. Those who managed more did so by virtue of status bestowed upon them by values propagated by those in authority, and thus do not really challenge the system.

Additionally, this diminished margin for resistance also hindered the children's ability to disengage from the roles that were being proliferated through their interaction with the teachers and staff. These 'situated roles', as described by Goffman, are symbolically defined by social interaction and ritual order. Analysing the social interaction among students and teachers in this chapter has indicated that the formal and informal organisation of this institution inhibits participation, and acts upon the premise that being disabled is a weakness stemming from a deficiency. There is a finality to their perception of this deficiency, as expressed in their interviews and conversations, and this is illustrated in their charitable care for the children, and their low expectations for their achievements. Forrester (2002), Mayall (2002) and James & James (2004) research point to the influence of such daily interactions and social dynamics with adults on shaping children's understanding of being a child.

Despite their dedication and hard work, the staff at the school was propagating medical, traditional and discriminatory constructions of disability. The children were being prepared to face the outside world by being taught how to conform to societal constructions and expectations of persons with visual impairment. This socialised the students into a 'disabled identity' rather than the identity of 'a person with a disability'. This is explored further in Chapter 6 which looks at how children in the institution define their sense of belonging at home and at the institution.

## CHAPTER 6 – OUT OF PLACE • FAMILY RELATIONS & BELONGING

### Introduction

This chapter addresses research question 3 concerning the impact of inclusive and exclusive practices on the social identities of visually impaired children. This chapter investigates notions of belonging to home and school environments among children at BAL to assess the impact that this has had on their sense of identity. The analysis in this chapter focuses on how the children place themselves in the world outside BAL.

During their childhood, through socialization, children learn about relational processes, social norms and social order from their primary caregivers and surrounding environment. This was indicated in Forrester's (2002) analysis of the influence of language and conversation on children's perceptions of their roles, and was raised in Mayall's (2002) examination of generational relations between children and adults. In addition to their interactions with adults, children also learn to relate to the 'real' world through interactions with their peers (James 1993). As these dynamics are imbued with social and cultural values, they are also the process through which children learn of their linkages, or belonging, to a particular group, and 'humans have a need to belong, to have a sense of themselves as members of particular communities with shared values and history' (Archard 2004: 83). It is during this time that children acquire a sense of social categories, relations and belonging that influences the successive processes of developing their sense of self perception and identity.

The issue of living away from home for disabled children who attend a residential school was sufficiently central that it emerged in all interviews with the children, their parents, alumni and the staff at BAL with little to no probing. Any discussion of the 'school' or 'home' brought about an

instant comparison between the two, which was then further elaborated. Everyone expressed the view that the children would normally be living at home and that the reason for the children living away from home was their impairment

This chapter analyses perceptions of 'belonging' among the staff, parents, alumni and students. Belonging to a place links to the formation of a child's social identity. The analysis explores the perceptions of each group as to where 'home' was for the children, and how the children expressed their sense of belonging. This chapter presents an analysis of the views of parents, staff and children of the environment at BAL, links between home and school, as well as links to the extended family and 'home' community. In the interviews with family members, a closer look was taken at the roles adopted by parents towards their child, and the family's perceptions of the child with a disability.

In discussing the issue of "home" in this chapter, it is interesting to explore the symbolism of the word in the English language versus Arabic. In English, 'home' is differentiated from 'house' in the sense that the latter is the physical structure, whereas the former has a more symbolic meaning, the transformation of the physical into the emotional. In prefixing it to words such as 'homeland', this symbolism is reaffirmed by attaching meanings of belonging to 'home'. The Arabic language, though prolific in its vocabulary of nations and belonging, does not carry a synonym to the word 'home'. In searching for an equivalent word, the closest in meaning would be something closer to 'nest', "*dawhu*" or "'eshsh", but that is never used in non-metaphoric discourse as the literal meaning applies to birds. "*Bayt*" and "*dār*" that are more commonly used would normally refer to where the parents or patriarch lived, and usually the house where the person grew up. Up until recent years, this house would have been a multi-generational home built and owned by the family, passed on through inheritance and shared by more than one of the sons' families. Though this practice has become less common, and fewer and fewer families own their houses, or still live in their villages of origin, they still identify with their homes as a place that belongs to the family,

and indeed, that the family belongs to. Until recently, children who had completed their studies and started working were expected to continue living in the family home until they were married, emphasising the sense that homes contained families not individuals. Street directions are made with reference to people's homes, and the equivalent of "The Browns" would be "*Bayt Brown*", "*bayt*" also meaning house.

The elaboration is not meant to confuse the physical structure with the cultural and social meanings of home, but rather to illustrate the strong symbolic relationship between the two in the Lebanese culture. The argument above additionally asserts that the essential feeling of belonging that is taught by families is often attached to geographical or physical locations as well. On a slightly macro level, the village or neighbourhood or refugee camp carries relevance in terms of the individual's group history and belonging. In a country with a rich history of internal and external conflicts, names of areas and villages are attached to historic events, as well as victories or losses. In the wake of the Lebanese civil war (1975 – 1990), villages also became aligned along religious and political lines as some village members were displaced to other areas of the country inhabited by like-minded groups. Though this mostly applies to the Lebanese community, geography also plays a role with Palestinian refugees in the country, where refugees from particular villages in Palestine settled together in the same refugee camps, thus identifying the camps with specific areas in historical Palestine. Therefore, the geographical link constitutes a part of the individual's socially recognised identity, where the connection is once again made to the group or family names who originate from there.

This link or belonging to a group or family, as is often quite easily recognised by society, reflects upon the individual's social status and that of his or her family. In all socio-economic groups of society, children of any family are expected to carry their family name proudly, as well as contribute to raising the societal status of the family. The Lebanese society perceives the children's achievements as a reflection on the family, as are their failures. Moreover, Lebanese

society attaches the family identity to the child, and that is commonly the first impression that he or she makes at any given event. In the same vein, loyalty to the family is held in very high regard and is interpreted as offering unconditional support to family members, especially those of the immediate nuclear family.

In light of these connotations attached to 'home' and identity, this chapter explores how these representations of home are expressed by the children and their families, and how this reflects on their perceptions of 'belonging'. As illustrated, this sense of belonging affects the social identities of the children. The argument explored here is that a loss of a sense of belonging to the family or 'home' within a society that attaches so much value to these lines of kinship will automatically lift the child 'out of place' and force upon him the task of reconciling this irregularity within his social identity.

## **A. Home Environment & Belonging at BAL**

Boarders at BAL returned home for the weekend if the parents are able to arrange for their travel home. Most of the children's families lived some distance from the school, and though some returned home every week, others did not do so for months. Most of them returned home for the weekend every fortnight, leaving the school on Friday at noon and returning on Sunday. This was in accordance with the school's regulations for boarders returning home on any given week. During the year that data collection was being undertaken, the school had tried to introduce the additional possibility of children going home on Wednesday night and returning to school the next morning. Only two of the children tried this option and it was short-lived due to cumbersome logistics as both children lived a distance from the school. Shortly afterwards, the school offered

buses to transport the children home every weekend, and almost all the families took this opportunity.

As BAL emphasises its academic role with the children, as illustrated in Chapter 5, it is perceived primarily as a school by the staff, parents and children. As a residential boarding school where children spend most of their days, to them, not living at the school would entail not being a student there, and therein lay their dilemma because they did not want to attend another school. This was expressly verbalised by children who had previously attended regular schools before coming to BAL, for they did not remember or recount this as a happy experience. In describing these other schools, some of the children mentioned the names, but all of them specified that they were not for blind children.

*Maroun: It was a regular school ... there were all types of people there, but I was the only one who was blind.*

*Adel: The school was in Zgharta. It wasn't for blind children*

*Kinan: They used to swear a lot. There weren't any blind students there*

*Munira: Yes, in Saudi Arabia. It wasn't for blind children*

While making these specific statements, the students' non-verbal expressions indicated that the fact that the school was not for blind children was sufficient explanation of why they could not continue to go there. One or two elaborated on this by referring to the difficulties they faced in performing academically at these other schools that did not have any adaptations for children with visual impairment.

*Adel (on why he prefers BAL to his regular school): And my father would hit me when I got low grades – I once got 1/30 in a Maths test. Now my brother gets hit by Dad instead of me! (smiling)*

*Maroun: I like this one a little; I've been here for seven years now. I didn't like the other (school) at all.*

Thus, BAL was the school where they could hope for some academic achievement, which would please their parents, and which was no doubt a boost for their self-confidence in comparison with their achievements at the other regular schools. BAL was the only school they had ever been to that took their impairment into account, which was an improvement on their previous experiences, and which made acclimatising to BAL worthwhile.

All the children who were interviewed expressed their desire to live at home. None of them thought of BAL as 'home'. They hated the food; they hated sleeping there, they hated the boredom when they stayed there at the weekends. The children would enthusiastically express how much more they preferred being at home than at BAL, for numerous reasons. It was where they had more fun, played more, where the food was better, where they got to hang out with their siblings, where they met some of their neighbours. One child seemed to sum it up quite succinctly when describing what he liked most about being at home and said *"The freedom. I have control over my time. Here (at BAL), we are controlled"*. (Kamal) Others voiced an overall rejection to living at BAL in that it was everything that home was not – *"Even, you know, I like (lentil soup), that is I love to eat it at home, but I can't stand to eat it here (at BAL)"* (Joseph).

The most frequently cited feature that they liked most about the school was the day when they went home. The only feature that they liked of their regular school was that it allowed them to go home every day. One of the children perhaps phrased it best when, upon being asked where he would prefer to be, responded *"I want to go to school at (BAL), but live at home."* (Ref: Ahmad's home visit)

This sheds light on one of the children's main dilemmas. On the one hand, their preference for being at home was clear, which spoke in favour of attending another school. On the other hand, they did not feel that they would fit into any other school, or be able to perform well there.

What was perhaps more pertinent to the children, was that it was the only setting they had been in where their impairment was shared by others, and thus carried less social impact within that restricted circle.

*Kamal: I prefer it here because we are all the same here.*

*Abed (alumnus): At (BAL), you don't feel like you're lacking or missing anything.*

Such comments revealed the students' sense of loss, weakness or difference from others around them, which were dispelled by being at BAL. BAL became a desirable place to be in because they felt their impairment was not emphasised which allowed them to fit in with a larger group. The value assigned to this feeling can be gauged by the growing sense of attachment that the students developed towards the school. During an interview with Riyadh, who is bright and has low-vision, our conversation strayed into the possibility of attending other schools. As Riyadh was telling me about surgical procedures that he had undergone which he felt improved his vision, I asked if this would now allow him to attend another school – a concept that he rejected.

*"But it would be difficult to go to a regular school, because of the atmosphere there and my friends being here. It has nothing to do with the actual classes or studies, I just wouldn't want to leave here." (Riyad)*

Riyad was one of the brighter students in his class, with low-vision, which afforded him a higher status at BAL than it would at a regular school where he might be the only person with a visual impairment. Riyadh's reaction strongly and clearly reflected his attachment to a setting to which he

had become accustomed, and where he had made a place for himself. This was also echoed by the alumni who, over their years at BAL, progressively preferred staying there rather than going home for the weekends, and who continued to visit the school long after they had graduated from it.

*Ruba: At the beginning, I wanted to go home all the time. Towards the end, I didn't want to leave (BAL) any more.*

*Omar Rammal: When you first saw me at (BAL) I was already attending university, but I would go up to (BAL) whenever I could.*

*Jamil: When I (first) went to university in Beirut, I would come up to (BAL) every weekend.*

As students of the school, their preference for staying there rather than going home for the weekends was linked to having more things to do at BAL than in their home neighbourhood that had not adjusted its physical or social environment to their needs. Thus, their attachment was to the place itself, which had become a home where they felt they belonged. After graduating from BAL, their trips back were also to maintain contact with this group of people.

Individuals at the school had become connected not only to the geographical place but to their peers as a reference group as well. Some of the younger students then attending BAL reflected this in their resistance to leave BAL and their friends, and in their reflections on who would be paired with whom within their school society.

*Kamal: "Miss, who are you going to marry here from the school?"*

Interviews with current and past students pointed to the contrast in social relations that they experienced outside the school.

*Jamil (alumnus): (after leaving BAL to go to university, it dawned on me) that over there (at BAL), I was limited to the twenty available people to befriend, the twenty or so girls with whom to go out with, to the school and its grounds, etc...*

They compared belonging to BAL as a place compared with what existed outside the school, and thus belonging to the school or to the outside world became mutually exclusive concepts. Consequently, to the students at BAL, belonging to the school and to its social group became firmly linked. These feelings were reinforced by the difficulties they faced when they ventured outside to attend regular high schools.

*Ruba (alumnus): In the last few years, I was integrated in the high school in Kfarchima ... Us blind students would also always stay together. The others couldn't really mingle with us.*

*Because of (the students') time in (BAL), they had absolutely no feeling of belonging to the outside world, including their family.*

*Omar (alumnus): Making friends at the regular school didn't come naturally to everyone ... Some of the (blind students) remained isolated at the regular school.*

*Ghina (currently integrated in a regular high school): It was just hard at the beginning, for a week or so, but then I got used to it. They're all very helpful at the school. But some of my friends are still finding it hard to be there.*

*Not just being in a new school, it's very different than here (at BAL). Here you're among people like you who are also blind, and it's different from being around students who can also see...*

*Jamil (alumnus): ... when I first started university, I felt like I had dropped there from outer space.*

This sense of alienation that they faced when they left the school contributed to their attachment to BAL and their visits there that continued after they had graduated. This reflected their sense of belonging to a reference group of visually impaired persons.

*Jamil (Alumnus): Some of the advantages of an institution – belonging to the place and the group. Think of the ex-detainees from the Khiam prison, they're having a tough time re-integrating into their areas and remain quite dependent on each other. BAL had all these features. We belonged to "the blind", and we had nothing to do with the outside world.*

This echoes much of Goffman's conclusions in his work on total institutions. The group of children under study at BAL were too young to have yet approached such a level of self-analysis. Yet their expressed reasons for wanting to remain at BAL point to the possible beginnings of such a process of social identification. Children who had attended a regular school before coming to BAL preferred being at BAL. To them, it was better than the regular school because they were not abused (verbal and physical abuse) and because they were not the only person who was visually impaired. The children have clearly asserted that BAL is not their home, and that it is not where they would want to live. Additionally, though they did not go to BAL of their own choice, they unanimously accepted, if not preferred, that this is where they belonged. They continuously stated how the other schools (the regular schools) were not for them. This not only refers to their academic capacities that were heightened at BAL, but to, as Riyad called it, "the atmosphere". Though the formal setup at the school left the children feeling controlled and, at times, unhappy; their friendships, the informal circles of support, their socialisation into the system at BAL is where they drew their strength. Retrospective narratives of alumni confirm this sense of estrangement from settings and contexts that they took part in outside of BAL. At BAL, the students developed a sense of identity and belonging not just to the school as their alma mater, but to this distinct separate group of visually impaired peers as well.

### ***'Home' to the Children***

In describing their time at home, the children excitedly described the fun and the freedom that they enjoyed there, playing with their siblings and cousins, or excursions with their families. The children also emphasised how they were cared for at home, and brought that up as the main difference between being at home and living at BAL.

*Maroun: I don't like sleeping here (at BAL). At home, the bed I sleep in is bigger and I sleep next to my mother ... and I am covered by a blanket and a quilt, not like here.*

*Riyad: But I like being at home, it's calmer, and there's love there. I'm more comfortable at home.*

The children who were interviewed all cited their strong relationships with their mothers as their main support at home. Their siblings were also their constant companions and playmates. The children recognised that these family members, and sometimes others, played a part in their happiness, gave them emotional support, but they connected that with being at home. These family members are not able to play that same role when they were away from home, in different circumstances.

Aside from their parents, their siblings figured heavily into the children's descriptions of home. It was with them that they played, visited or hung out. It was a group of children where they naturally belonged, and who freed them from adult supervision. (Ref: Children's interviews) Strangely enough, this was not the case with some siblings who attended BAL together. Apart from one set of siblings who looked out for each other and asked about each other at BAL, the others did not deal with each other at all, and I discovered that they were siblings by sheer coincidence. It is not uncommon for siblings to ignore each other in the school playground or during the school day, but these children were in residence, and living in the same dormitory. Though their seeming disregard towards each other may not necessarily reflect the absence of emotions or family bonds, it did seem to indicate that this was not the place for them. It was almost as if in this setting, at BAL, these were not the ties that were needed to make them stronger, nor was it the place for their family relations. (Ref: Jaafar and his brother, Kinan and Bakr, Zeinab and Ahmad)

The children's personas or characters at school were those that allowed them to manoeuvre and survive through the formal and informal pathways and hierarchies described in the previous chapter. Contrary to the system at school that perceived them as a homogeneous group, 'home',

is where they could be special and different. Their behaviour at home compared to at school, as observed during the home visits and fieldwork, illustrated that the two were frequently different. What was undoubtedly clear, however, was that 'home' was the one part of their identity that differentiated them most from everyone else at school. Their presence at school, and as a boarder, is definitely what differentiated them the most at home. When describing their time at home, Samia & Munira were each quick to point out that they were "*the only one (of my siblings) who goes to boarding school*" (Ref: Samia & Munira's interviews). Such statements were not made proudly, as one would if they were the only one of their siblings on scholarship at a prestigious school. They were made with the understanding that they were away from home because they have a disability. Yet their impairment was never brought out as an issue while at home, the issue was that they were separated from their families while their siblings were not. Thus, in their minds, their siblings continued to experience the emotional support and freedom all year round that they only experienced during their brief stays at home. Some of the alumni attributed feelings of detachment from the family and home environment to this experience.

*Ruba: Because of their time in (BAL), they had absolutely no feeling of belonging to ... their family. I'm not sure if this has come about because of an internal feeling because the parents sent them away and that the other children (their siblings) were loved more and treated differently because they stayed at home.*

*Jamil: My first week at the school was a terrible struggle. I was very angry at my parents thinking "how could they leave me here!?"*

The children's relationship with their home and family had become altered from what they knew prior to being sent to BAL, and much of their efforts while at home were attempts at re-stabilising or recreating rapport. In doing this, they responded to all the factors that they were subjected to, such as their siblings' experiences at home, and their parents' perception of their disability. In some instances, these were not positive influences on their relationship with their family.

*Jamil (alumnus): Some kids were treated very badly at home because the family didn't want the disability in the house.*

*The dormitory supervisor when talking about Mazen:*

*You notice it, how he becomes aggressive and beats up children who receive calls from their parents. His parents never call him. He is not cared for at all at home. Would you believe that they would leave him here for weeks without taking him home for the weekend?*

At each of these extremes, whether home was where they were greatly cared for, or where they were rejected, the children within the age group under study understood that their natural place was at home. Their parents' perceptions of their disability is discussed in the following section, but the main issue that the children struggled with in maintaining their relationship with their families was the uneven distribution of their time between the school and home. While in school, the children were in a world that was geographically and figuratively detached from their families and their homes. With time, this strengthened their feeling of belonging to the school, and detracted from their common ground with their family members at home.

*Jamil (Alumnus): Between 1971 (when I lost my sight) till 1976, I had no contact with my old sighted friends, or my home or my village. BAL was central to my life. Then the war broke out and I spent more time at home, met my friends and made new ones. Then I wanted to go home more.*

The more time that the children spent at BAL, the more they acclimatised to living there, and the fewer opportunities they had for meeting and making friends closer to home. In a sense, the circle of siblings and cousins at home became too constricted in comparison to the comparatively larger student population at BAL, unless circumstances intervened to reverse that ratio. Eventually, it was factors such as these, which had first contributed to the children feeling out of place at school, that later influenced the children's sense of feeling out of place at home.

*Abed (alumnus): After (BAL), I found it very hard to go back home... (home) was a very different setting... it was very hard to re-integrate into my village.*

Similar sentiments were expressed here by male and female alumni hailing from different parts of the country, and from different ethnic and religious groups. Colleagues of other alumni referred to the difficulties their friend had faced re-acclimatising to a conservative home environment compared to her own comparatively liberal ideas (Field Notes, 11/Oct/2001). Others struggled to find a useful role for themselves at home, where they felt they could contribute little around the house (Ref: Jamil's interview).

The children's relationship with home and their families was not a static one. In time, different elements weakened or strengthened their links with home as the children grew older and developed, and as their needs changed. In the process, their sense of belonging and subsequently their perceptions of self changed. This not only referred to the connections that were implied between belonging to the school and to a separate social group of disabled persons, but also to the changing relationship with family and home that affected the students' sense of individual and group identity. In many ways, this shift fell in line with predominant, social perceptions that clustered persons with specific disabilities into homogeneous groups, irrespective of their background or family identity.

## **B. Creating Links between BAL & Families**

The children would occasionally attempt to create links between BAL and their families. BAL was as far away from their home and family as they could imagine, and yet they wanted to be a part of both. In developing these links, the children were going through a process of negotiating their place at home in light of the fact that they no longer lived there full time. It served not only to introduce their family to their life at BAL, but also to search for their role at home which was now changed, and different from what they saw in their siblings who did not live away from home.

As discussed in Chapter 5, the parents' had limited involvement in events at the school, and those who visited the administration when they arrived to pick up their children for the weekend frequently received feedback that related purely to the child's academic performance. The school considered its role with the children and the parents as purely academic in nature. The only exception was in the role carried out by the psychosocial coordinator who maintained the children's medical files and undertook an annual visit to most of the children's homes. Even then, however, the home was visited in the absence of the children and the focus was on either counselling parents on handling their child or discussing their academic progress. Though the parents' committee did call for meetings, which were normally attended (and often led) by the director and psychosocial coordinator, these rarely discussed the children as much as they addressed financial issues and the latest stipulations or regulations introduced by the school or by the Ministry of Social Affairs.

The School took some measures to maintain contact between the children and their parents, but these were informal or unofficial as the school did not consider this part of its responsibilities. One such measure was to be somewhat lax in allowing the children to call their parents from the school switchboard. This may be related to the fact that, as a non-profit institution recognised by the Ministry of Social Affairs, BAL was exempt from paying phone bills. However, as the whole school operated on only two phone lines, such phone calls were kept short.

*Yola kept looking out the window to see who was on the phone downstairs. She yells out at Kamal to wrap up his conversation – "Unbelievable! He can't wait for his mother to call him, he has to call her every day!" (Field Notes, Nov 01: Pg. 21)*

In searching for more consistent links to the families through the school, it is clear that none have been systematically set out. Parents are invited to attend the Christmas and end-of-year performances by the children, but these are also fundraising events where donors and other key personalities are given the front seats and the attention. There are no other exhibitions executed

by the children that the parents can be involved in, nor are the parents invited to attend the weekly Friday performances. The parents, for their own reasons and circumstances, were apt to follow the school's minimum allowed standard of contact with their children while in residence. Similarly, when the school had attempted to set something up with the parents, it had failed usually due to the parents' lack of time or effort, as was illustrated in Chapter 5. As a result, the onus of maintaining links with home while in residence at BAL rested on the children.

The children appeared to be more concerned about involving their families with their life at BAL than vice versa. The children would avidly recount stories from home to their friends and to the adults in residence, and there was always ample time to do so in the week or more that they spent there in between visits to their families.

*As I walked into the 'playground' today, some of the boys rushed to tell me some of their stories from their weekend at home. They were each trying to top each other with what their weekend had consisted of, but all of them cracked up upon hearing Ayman's story (for the umpteenth time) about how he and his family were turned back from the Syrian borders because his sister had forgotten her ID card at home. (Field Notes, 23 Oct 2001: 18).*

Carrying news in the opposite direction was always time restricted by the comparatively short duration of their stays at home, during which a mutual exchange was to take place to also update the children on events at home in their absence. Besides which, perhaps only recounting stories from their time in residence at BAL was not considered adequately interesting for keeping their siblings and parents involved with their life there. The children took homework with them on their home visits, but it was not shared with their family members as homework was usually in Braille. Additionally, out of their respect for the school administration's expertise in dealing with their visually impaired child, as discussed in Chapter 5, in their interviews, the parents implied that they did not dwell on the details of what the children went through academically (Home visits transcripts). Their main concern was in making the children's stay at home special.

However, there were some incidents during the period of data collection that indicated the children's desire to carry a different picture of their time in BAL back home, focusing less on their special ways of learning and more on achievements that could be considered 'normal' to their parents and siblings. Children who had done well in their music lessons during the week would sometimes persuade the teacher to allow them to take their instruments home with them. This was an additional incentive for the children who could then share their musical performance with their family.

During the group work sessions, the children were constructing frames of a storyboard with play dough figures. These were then to be photographed and mounted as a mixed play dough – a photo novella. When the camera was brought in for this purpose, all the children (those with low-vision and other who were severely visually impaired) wanted photos of themselves with whatever they had just created from play-dough. When distributing these photos to the children, including those that they had taken themselves, they would comment on how they were going to show them to their mothers. After all, this was an alternative medium through which to bring their mothers closer to knowing what they were doing at school outside of the classrooms, and how they were spending their time away from home (*Field Notes: Pg. 24*).

To the children, creating these links was important to them as a means of remaining connected to their families. Being far away from home, where their siblings have remained, the children sought out additional attention from their parents, and rejoiced in any such sign.

*Tony rushes towards me and says: "I spoke to my mother today!! And she was the one who called me, I didn't call her..." (Field Notes, 7/Nov/02: Pg 22)*

For the children with siblings, it was also a way to compare their different activities and achievements and establish a sense of 'self' in comparison to their most similar peers.

This dynamic naturally depends on the situation and status of each family. Children coming from abusive households may adopt different methods and attitudes towards sharing their life at BAL with their family members at home. In all cases, as the children spent more time at BAL, the efforts that they placed in building these bridges was gauged by their sense of belonging to their homes and to BAL. Some may decide that they simply do not belong at home, like the alumni quoted previously, and forgo these efforts altogether. Others might develop a balance between their separate lives at home and at BAL. The younger group of children under study appeared to still be exploring their way between the two. Their struggle with their desire to be in both places was still ongoing, as was their process of defining themselves at home and at school. Within the homogeneously defined group at BAL, their stories from home served to add to their individual character. At home, being the most different from their siblings in the way they spent their days, stories from BAL were meant to narrow the gaps and bring them closer to the normalcy of their siblings' lives. Throughout this process, the children are negotiating their social identities as a child with an impairment, and as a member of their family.

### **C. Community Links**

In their interviews, very few of the children were able to describe their surrounding home community in any detail. Some spent most of their time indoors, with the occasional visit to a relative's home. Boys recounted many more outdoor stories of their time at home, and description of the landscape that they walked on. The girls, on the whole, did not go out much when they were at home. When any of the children did go out, it was usually with a sibling or cousin.

*Adel: "My cousin leads me around if I can't see"*

*Maroun: "I go all around the village with my brother. There are wild fields everywhere and no streets, and my brother and I look for and collect scrap metal and the like."*

*Ahmad: "I walk through the camp all alone, everyone knows me there and I know the area well."*

Children who did not venture outdoors naturally did not have strong links with their community. They also did not seem to be able to handle the community's attitudes towards disability – *"The neighbours make fun of Ayman, this doesn't encourage him to play in the building much"*. (Ayman's mother) Community attitudes were also cited as one of the parents' reasons against including their child in a regular school nearer to home – *"It would ... be difficult for him to be included in a regular school here ... if there was one that would accept him. The community, the parents, the dominant mentality would not treat him well as a child who could not see well"* (Ayman's mother).

*"I think it's better to be at BAL when you're young, because society does not include a blind child"*  
(Alumni – Abed)

Furthermore, all alumni attested to how difficult it was for them to return to their home communities after having been away at BAL for several years. At times, it was the student who could no longer find a way to fit in at home, as illustrated in earlier quotes, and at other times, this difficulty was shared by the family as well.

*When Ruba (alumnus) returned home from (BAL), her family had a very tough time accepting her again with her liberal thoughts and habits that were not considered socially acceptable by them or by their neighbours in the camp. (Field Notes, 11/Oct/2001, Pg 31)*

The children's and parents' accounts confirm the absence of any strong links with the neighbouring community. One gratifying relationship for the children with the community was when they performed. With the large focus on music, BAL boasted a good amateur music group and choir consisting of the students. At least once a year, either at Christmas or during Ramadan or both, the children visited other institutions to perform for them. The year this research was

conducted, they had visited a home for the elderly in Beirut. The children enthusiastically described the trip to me; the reaction of the audience, the presents they gave and received. They were so excited at having provided a service, or given something to others, especially people whom they considered less fortunate than themselves.

*As for the choir, the school would arrange for the students to visit other centres (orphanages, old people's homes, etc.) to sing and give present to them around the Eids, and the children would be talking about it throughout the following week. They would wait to see the treat that they would be receiving in return, and they would talk about the "poor" people that they saw, who were happy to hear them sing. (Field Notes: 25)*

Performing was also the easiest way in which they relate to their immediate community at home –

*"The house gets very busy when they're here. Ahmad plays the organ, and in the summer, everyone's on the rooftops listening to him and his sisters play music. They all love them here." (Father of three children who attend BAL and live in a Palestinian refugee camp)*

Children whose families lived in tightly knit, small communities usually lived near several members of their extended family and had more freedom to explore their neighbourhood and become acquainted with the people there. Those who did not had little to no spontaneous contact with anyone outside of their family's home. The girls gave minimalist description of their neighbourhood that would seem to indicate that they did not roam about or explore their surroundings at all, neither with their siblings or anybody else.

*Samia: there's lots of greenery ... don't know about the buildings around us... there aren't too many cars... I don't go to all the places around us.*

*Munira: we live in a building, it's three storeys high...*

It is, perhaps, insensitive to ask a child with a visual impairment to describe his or her neighbouring environment at home. Except that one would argue that they had no trouble

describing their home, highlighting fixtures or individuals there, and those who did roam about were able to give some detail to their surroundings. This pointed to their relationship to particular spaces, and the subsequent meanings that these spaces carried (Halldén 2003). While at BAL, the children within the study group (7 – 12 years old) had no contact with the outside community, except for their occasional performances. At their age, they were not allowed to leave the school grounds at all, and that is where they spent most of their time.

Visitors to the school, whether through a class field trip to BAL or donors or inspectors or the like, reaffirmed their difference.

*Jamil (alumnus): ... or when we used to get visitors at BAL, it was just so odd, as if the visitors were coming to look at us, as if we were some 'shrine' or something. We were pleased when we had visitors because we would have better food for lunch and the heat would be turned on (laughs), but they would just watch us, as if we were from another planet.*

Accounts of visits outside the school in integrative settings contributed to this feeling as well –

*Abed (alumnus): I remember being sent to this YMCA camp ... when I was ten years old. There were only seven or eight of us blind people and the rest were all sighted. I felt very lonely. All of the activities required sight.*

The links between them and the outside community, that is, the wider society, whether at home or at BAL, appears interspersed with obstacles that make it difficult for them to develop any steady bonds.

*Abed (alumnus): ... (a) negative aspect about BAL – you miss out on the community aspect.*

## **D. Parents' Roles & Family Relations**

### ***Family, Belonging & the Arab Society***

This section analyses home visits with parents and interviews with the children and alumni to investigate the parents' perception and views of their children's disabilities, and their lives at BAL, and their place in family life. The family unit plays an invaluable role in the life of the children. It is through their families that children learn the values and traditions of their culture, and about attitudes and principles prevalent in society, and began to form their social identities and sense of belonging.

This is relevant to all societies, no more so than the Arab one where there is a history of tribalism and wider belonging to a group such as a tribe or a clan (Sharabi 1999): 37) village or religious sect. These wider affiliations support the role of the extended family in the lives of its members, as well as the collective identity of the family and its members. This is heightened in times of crisis, and war when the circle is widened. Similarly, the birth of a child with an impairment, reflects not only on the child, but on his or her nuclear family as well.

### ***Adjusted Parental Roles***

Analysis of the data show that several factors shaped the parents' reactions and perceptions of their child's impairment. Social perceptions and pressures constitute some of these factors, but on a more personal level, the parents struggled with their own feelings of inadequacy at handling their child and the impairment. On the one hand, this inadequacy stems from the economic strains of being able to care for this child with his or her additional needs, and on the other is the confusion of how to best rear and nurture the child and deal with their impairment.

The parents who were interviewed gave detailed narratives of the discovery and diagnosis of their children's impairment, up to the point of their decision about schooling, after which the school was then described in simple broad statements. Possibly reflecting the depth of their involvement in the earlier process, and their limited involvement in the school.

As they started to suspect that their child was not responding visually, all parents sought medical help. They described what triggered their suspicions that something was wrong, and the several steps that were taken before anyone was able to diagnose their child's impairment or its causes. Finding the cause was crucial to their hopes that the problem could be reversed and the child could be cured. It was also essential for them to do so in order to allay their sense of guilt for being possibly responsible for their child's impairment. Detailing the steps and mentioning the tests and the medical centres visited provided confirmation to the interviewer, and possibly to the children who were present during the interview, that no expense or effort was spared. It also reflected their anxiety at that time, and their sense of powerlessness.

*Ahmad's parents:*

*Hala, our second-born child, was born when we were in Libya. We were by ourselves and didn't really know very much of what to look for in terms of the child's development. We took her to an eye hospital there and they said that her retina was weak.*

*We took her to several doctors and ran many tests for 3 years.*

*When we came back to Lebanon, we even went to see a priest and a sheikh that people had told us about. But nothing changed.*

*Ayman's family*

*When Ayman was first born, I didn't notice that there was anything.*

*He was walking at a year old, and everything seemed to be fine.*

*When he went to school, they tested his sight, and told me that he couldn't see well.*

*I couldn't accept it at first. I kept insisting that it was just crossed eyes. I was very upset by it all.*

*They said that 'Rosella' affected his optic nerve.*

*Riyad's Family*

*When Riyad was 3 months old, we felt something was not right.*

*We had his head scanned and found out that his retina was damaged.*

*We went from one doctor to the next, but none of them had a solution.*

*Naji's Family (son is included in a regular school)*

*You are going to laugh at me, but I immediately knew that there was something wrong, when Naji was just a newborn.*

*I wanted to have him checked out at 1 month, but my husband resisted. After all, he was reacting to a camera-flash or the sun. But I felt he was cross-eyed.*

*My sister-in-law compared him to the development of her own children and felt that he was not seeing right.*

*We discovered that it was a problem caused by heredity. We have a cousin with 3 blind sons. It was due to consanguinity.*

The parents had all taken whatever measures available to them to reverse or heal the child's impairment, and had finally accepted that this was not possible. In some interviews, this was almost presented defensively, as if this was not a reality that they had been quick to accept. Aside from the parents' natural desire to relieve their children of impairment, reactions from the extended families were rarely supportive of the children and their disability, as discussed in more detail later on in this chapter, and the parents' defensiveness spoke of a need for their children and their impairment to be accepted as God's will.

The parents were struggling to learn how to deal with their child. Faced with the pressures of discerning the optimal solution for caring and educating their child, and the pressures from their extended families. The parents' feelings of helplessness were accentuated by the absence of social support, guidance or advice. The only guidance they did receive was to send their child to an institution or special school, such as the BAL. All the parents who were interviewed had found BAL through word of mouth, and were grateful that they had found a solution to their dilemma.

*Ahmad's family*

*My wife's uncle works in the Social Affairs department at UNRWA. We had been told about schools in Jordan. And then he told us of a school in Khaldeh, but we felt that was too far. And it was during the war and there was the ... check-point to cross, which was a problem. It was also winter and it would have been difficult and taken a very long time to make the trip through the mountains to avoid the check-point. So we kept the children at home (until after the war)*

*Ayman's family*

*Dr. Mo'ataz directed me to the school at BAL. Ayman went there when he was 5 years old.*

*Riyad's family*

*We had a relative over at BAL, so we sent Riyad there.*

The surrounding pressures to send their child to an institution were not to be taken lightly, as related by the mother of a child who was included in a regular school. The mother was adamant about not sending her son to a boarding school and, by chance, stumbled upon an organisation that supported the inclusion of children with visual impairment. However, the decision that she and her husband took was faced with opposition from everyone.

*Naji's Mother:*

*Then I found (the organisation) through a 2-minute spot about them on TV. There was some coverage showing a child reading Braille and included in a regular school. So I contacted them to see what they could do for Naji.*

*I got resistance about inclusion from everyone – family, friends, etc. A 35-year old blind cousin advised us against inclusion. Even my uncle who has a PhD in child psychology and works at the Ministry of Education opposed our decision. This really scared me a lot. Almost made me change my mind.*

*Everyone was against including Naji in a regular school. And when we were living closer to Hamra, and our neighbours knew us and Naji, one of them started telling me about the (special) school for the blind. That wasn't all, they all came to visit me – (three institutions for blind children, including BAL), all of them – all trying to convince me to send Naji there. But he had already started nursery school and was doing fine, and I didn't want to move him. But they kept insisting, telling me things like "You are committing a crime" and "God forgive you". But I just wouldn't do it.*

This was a family that avidly searched for an educational opportunity for its child, and coincidentally found it in the form of an organisation that met the main criterion the family was searching for; allowing the child to go to school while still living at home. Other families were not aware of such an option when it was time for their children to go to school. Additionally, whereas this family, who insisted on including their child in an inclusive school, was able to obtain the technical support that it needed in an inclusive organisation, others saw that same type of support in the institution.

Aside from these social pressures, to the parents with children at BAL, finding the school was a relief not only because the parents faced difficulties in identifying schools in their neighbourhood that would accept their child, but also because they were having trouble rearing their child at home.

*Ayman's mother:*

*It wasn't easy for me to send him. But Ayman was having a tough time at home, he wasn't accepting his predicament. He was always angry or nervous. It all changed when he went to (BAL), he calmed down considerably.*

To the parents, the school not only represented an educational opportunity for their child, but it also offered a form of professional guidance and support that they longed for.

*Ayman's mother:*

*After he had gone to (BAL), he started getting seizures – he would stiffen up and get headaches, like “closed bones”. He had to take some medication, which (BAL) were very good at taking care of and handling, and then it eventually passed (no more seizures).*

*I used to spoil him a little, but then (the psycho-social coordinator) pointed out to me, that I was doing him more harm than good, so I stopped.*

Not only was the school educating their children, but the staff at the school had also become their partners in raising their child. In their search for diagnosis and treatment, the parents consulted an assortment of professionals. In their quest to decipher how to work with their children and provide them with an education and training befitting their impairment, they now turned to the staff at BAL. The parents were still adopting a medical model to their children's disability, which had carried over from the medical professionals to the educational professionalism that they perceived at BAL. In the expert role that the parents ascribed to the administration and staff at BAL, their customary parental role was being adjusted such that they were sharing it with the staff. Not to mention that their child was now spending more time with the staff at BAL than at home with the parents. In a

regular classroom, teachers would normally tread a fine line in dealing with the children, such that incidents in the classroom did not conflict with standards and values held by the family at home. At BAL, this formula was now shifted such that parents did what they could not to challenge or be in conflict with what was being done at the school and in residence. The parents' reasons and rationale for behaving in such a manner related to the issues of the school's expertise and economic power that are discussed in Chapter 5. The outcome is that they became 'weekend parents' taking on a more limited role as parents. Subsequently, the parents' perceptions of their children and their disability grew on a time-stunted trajectory, and remained within the medical framework that had influenced their original decision to send their children away to a special school; because they were disabled and required special care. When the children were diagnosed, it was recounted to them as a medical condition, which is how the parents continued to view their child's visual impairment. Within that framework as well, they assigned a rehabilitative aspect to the children's time at BAL and expected that their children would emerge as individuals who had overcome their disability, as was indicated by their expectations for their children's future. That is, that the BAL would assist their children in becoming 'normalised', and thus able to re-enter society and approximate the parents', and society's, expectations (Chase 2000).

In the meantime, the parents engaged what little time they spent with their children by overcompensating – either actively spoilt them or treated them differently from their other children. As part-time residents at home, the children were excused from many of the chores as compared to their siblings. During some home visits, it seemed as if the child was being treated as the honoured guest.

*Ahmad's home visit:*

*Grandmother: The (blind) children are very special to their father. Sometimes, he would kiss Ghina's hands and feet. She is very special to him.*

*Father: I want to build a room upstairs for Suha and Rania so that no one touches their stuff when they're away.*

*Ayman's mother:*

*I would always say that I want to marry off all the children and have Ayman live with me. He would then say "You don't want me to get married?! In that case, I'm going to get married first!" And I tried to explain to him that that is not it at all. Of course I want him to get married, but I want him and his wife to live here with me so that I can serve him.*

An alumnus ascribes this preferential treatment to the continued sadness experienced by the parents, and perhaps even their guilt.

*Abed (alumnus): the parents remain sad, and they just let go ... they feel it's bad enough that the child is blind, let him at least get his way at home...*

It appeared as if some parents try to atone for their children's disability and their corresponding time away from home by excessive emotions and preferential treatment. As indicated from these interviews, they are by no means surrendering their role as parents to the children, but have in some ways compartmentalised their tasks and responsibilities to the children's time at home, and to the future. For the period of time that the children are students at BAL, the parents' decisions fall in line with those of the school's administration. Though the siblings only recognise and internalise the treatment that takes place at home, the children who attend BAL sense the imbalance in their parents' roles and accordingly adapt to it by recognising the role that is being played by the staff at BAL. This gradually shapes their links to their home and family, and to the school.

It is worth noting that the insight provided by this collected data was from parents who were reachable and who agreed to a home visit and interview. Many of the parents when introduced to the research project during a parents' committee meeting, noted on their questionnaires that they would welcome being interviewed for the research. Not all parents were present at this meeting owing to a range of factors. I interviewed six BAL parents and three parents with children in inclusive settings.

Parents who had sent their child to a regular inclusive school were in need of the same type of expert advice as the parents of the children at BAL. One of these parents steadfastly asserted her reasons for inclusion, having been willing to have the child home-schooled rather than send him to an institution, stating *“If I were to send him away, he would become a stranger to the family”* (Naji’s family interview). The NGO played a similar expert role as BAL, except that it was conditional on the parents’ involvement with the programme in terms of working with the child at home. The child was included in a school that was near the home, which naturally made it easier for parents to participate. The parents were able to attend mini-workshops at the school that offered ideas for developing the children’s motor skills, personal care and orientation using material that was accessible to all (GK Pre-school notes). Access to the school was easier, and the parents could be as involved as they wanted to be. The school encouraged partnership with the parents.

*Naji’s Mother:*

*I worked very closely with the teachers and with (the NGO) to prepare his material in a medium he could use. I used to construct all his 3-D models, and tactile images on paper. I even learned Braille with Naji as he was learning it. It’s not all that hard.*

Though this was perhaps one of the more active mothers, contact with the school and the teachers was generally much more convenient when the school was in the same neighbourhood, and parental involvement was thus higher (GK Pre-school notes). As a consequence, the parents (and their children) progressively became sufficiently empowered to take control of their lives as the NGO’s gradually phased out their involvement in the process (Naji’s family interview).

The other outcome from the parents’ involvement in their children’s school lives and remaining an active party in decisions concerning their children, is the effect that this has on their own perceptions of their children’s disability. This is discussed in more detail in the following sections of this chapter.

## *Siblings*

The visually impaired children, in their interviews, consistently referred to their siblings as their playmates and as their support. The siblings were the ones who freed them from adult surveillance and granted them the space and protection to venture and play outdoors. They were also their first and main peers who were not visually impaired.

*Maroun: "I play the organ, drums, oud and derbakeh with my brother."*

*Ahmad: "I visit my sister's house."*

*Samia: "I play with my brothers and sisters... even if we fight, we immediately make up."*

*Ayman, who is enamoured by cars and had played around with mine on several occasions, saw me parking my car, and I was met at the foot of the building by him and his brother Alaa, who accompanied him there, either for guidance or for moral support. (Ayman's family interview)*

The siblings were the children's steadfast support, and the consistent group of children that they had a relationship with other than their classmates at BAL. In addition to their classmates, the children repeatedly cited their siblings as their playmates and companions.

The siblings were not interviewed separately or in depth, but observations of their interactions with their sibling with visual impairment illustrated that they do not always proffer the same preferential treatment as their parents. The siblings were candid in their behaviour towards their disabled sibling, whether in being protective or resentful, just as they were with any of their other siblings. In the larger families, there was usually one particular sibling who was very close to the disabled child, sometimes younger, sometimes older. Yet they were clearly interested in this sibling, all of them choosing to be present during part or all of the home visit (Ahmad & Ayman's family interviews).

*Ahmad home visit: Suha (who is visually impaired) is very attached to Rana (the youngest child) and is always fixing her hair and taking care of her.*

*Ayman's family home visit: Mayssa (older sister) even thought of studying to become a teacher for the blind to be with him.*

*Abed (alumnus): my own brothers and sisters used to (spoil me and) put each spoonful in my mouth (when I was old enough to eat by myself).*

The time that was spent at the homes with the siblings was insufficient to assess whether or how their actions were influenced by their parents' actions, but their contributions to the interviews illustrated that they followed their parents' lead in the social construction of their sibling's disability. In general, all observations generally reflected what one would expect in any household of children where one was being treated differently. Both extremes were portrayed during one home visit to a family with three visually impaired children out of a total of seven children. The oldest boy Ahmad, was the fifth child in the family and the last one to have been born with a visual impairment, and had a younger brother and sister. The brother displayed several signs of sibling rivalry – avoiding being present during the visit which was clearly about Ahmad, and having broken a gift that Ahmad had received earlier that day. The younger sister, on the other hand, was hovering around Ahmad to help him out, and immediately offered her present to replace Ahmad's broken one (Ahmad home visit). An insufficient number of home visits was conducted to allow for generalisations, but it appeared that the siblings treated the child with the disability either in the same preferential treatment as their parents, or reacted to it by behaving in exactly the opposite way. The scene that played itself out in Ahmad's home would also alert one to consider how the duties or responsibilities typically attached to birth order are also affected from the siblings' point of view. As the older son, Ahmad would normally be expected to take on more responsibilities and chores, which he did not and yet was still being treated preferentially. During his absence while at BAL, it is possible that his younger brother was playing the role of the older son. It is possible that,

with the disabled child being away for most of the time, a new order is instated among the siblings, which is altered upon the child's return, and leads to the siblings' differing reactions.

As mentioned earlier, the siblings constitute the only other reference group of peers for the children with visual impairment outside of the group at BAL. Consequently, relationships with them contribute to their sense of belonging to the family, and to their identities in the wider society.

The extended family usually figured heavily into the lives of its family members, especially the children. Interviews with the children and parents offered a range of accounts of the involvement of the extended family as a result of the child's impairment. The children copiously referred to their uncles, cousins and grandparents as the people whom they played with or visited while at home, with very little reference to anyone else, implying, perhaps, that they did not visit any other homes than those of their relatives.

*Maroun: (When I go home...) I visit my uncle's (father's brother)*

*Kamal: On Sunday we go to visit my grandfather's house*

*Riyad: On the weekends, we go to visit my cousins in Sin El Fil (Beirut). My cousins are older than me and I like playing with them.*

*Munira: When we're in the mountains (on the weekend), I like it because we go out to visit our aunts and uncles. They live near us.*

*Adel: My cousin leads me around if I can't see.*

The extended family appeared to be important in understanding and including the child and his/her family, especially in instances where other family members had a visual impairment as well.

*Ayman's Mother: We have relatives who are blind – one of Ayman's uncles, an aunt and a cousin (female) are all blind. It is hereditary. So the family did not find issue with Ayman being blind.*

This type of understanding, however, was not common to all situations, with the extended family sometimes being an additional obstacle to tackle when dealing with their child's impairment if it was perceived to affect their social standing.

*Naji's mother: We discovered that it was by heredity. We have a cousin with 3 blind sons. It was due to consanguinity. We did some research and it was unbelievable with all the intermarrying ... The family fought this reputation. They accused us of trying to give them a bad reputation, that their kids will be blind. But it's the truth.*

*Riyad's father: What is the family going to say? We just resisted the question totally. Some of them reacted badly.*

Whether the extended family was supportive of the child and his/her parents or not, they consistently seemed to play a role in attempting to find a solution to the child's 'problem'. Members of the extended family were one of the sources recommending institutionalisation and sometimes leading the parents to BAL, as was illustrated by narratives from the parents (Ref: Riyad home visit, Ahmad home visit).

It would seem as if the extended family, though not able to reject one of their own, was a formidable reflection of prevailing attitudes towards disability. As a result, the extended family often played a role in branding the child or separating him/her from the family, either actively by advising that the child be sent away, or indirectly by cooling relations with the child's parents. This not only exerted pressure on the parents, but also influenced their social construction of the child's disability.

## E. Perceptions of the Child, Representations of the Disability

In *Childhood Identities*, Allison James proposes two ways in which parents perceived their disabled child as either being “differently normal” or “normally different” (James 1993): 44). The former category subscribes to a broad definition of ‘normal’; it acknowledges different versions of ‘normal childhood’. The latter, on the other hand, emphasises the difference rather than the ‘normality’ and is “shaped by a more homogeneous and restricted conception of ‘normal’ childhood” (James, 1993: 50).

The data from both parents and siblings reflected that they perceived the disabled child as ‘normally different’. They rationalised the child’s need to attend a residential special school due to his/her differences from other children attending regular schools, yet maintained a hope that this would allow the child to compensate for these differences to ‘normal’ standards. This appeared in their occasional assertions and insinuations of how ‘normal’ their child was – within the traditional concepts of ‘normal’ – all the while highlighting their difficulties and differences. At times, it would seem as if they were in total denial of their child’s impairment – “*I wanted him to be an eye doctor...*” (Ayman’s mother)

Practically all of the families are of low socio-economic status whether from urban or rural settings. The low to medium level of education of the parents was reflected in occupations and employment and the overall attitudes and perceptions that were upheld and propagated within the community that they lived in, as indicated by their neighbours and expressed by their extended families. Several families described discriminatory behaviour from their neighbours towards their visually impaired child, frequently leading them to restrict their child’s movement in the neighbourhood. Similarly, the disabled child was rejected by some extended family members, as highlighted by some of the parents (Ref: Ayman’s family interview, Riyadh’s family interview, Naji’s family interview). These were the main reasons that led them to send their child away to a special school

– because they perceived it to offer a better educational opportunity than the neighbouring schools, and because they would be seen by their community as having taken the appropriate course of action by removing the child from ‘normal’ circles. They perceived the child as different because everything has led them to believe that the child was not capable of running the same course as his/her siblings at home and at school.

Though the families were very supportive of the child and missed no opportunity to express their love and affection, but they were the ‘weekend’ family who were being relegated to the margins of the child’s social development. The children were perhaps considered exempt from social responsibilities in the home due to their disability, because they were seen as different, and largely absent from family, community and social activities. Yet these are still the guidelines that society and the family continued to employ to assess social development and coming of age. In the absence of alternative criteria, the children were being seen as children for a longer period of time. This falls in line with what was described as the tragic spoiled identity in Chapter 1, Section B, where the constructed disabled person was one that should not be burdened with social responsibilities and decisions (Finkelstein 1993; Oliver 1996).

The adoption of the medical model of disability by the parents has been illustrated in this chapter, and this has contributed to the construction of the disabled child as medically ill, and as disadvantaged and needing support. What also emerges from the parents’ narratives is the construction of the ‘supercrip’ who is perceived as superhuman for being able to achieve any worthy feat despite his or her impairment. The parents feel that the children will be accepted by society if they are able to overachieve in any particular task or field such as music or education.

*Ahmad’s father:*

*Most importantly, I don’t want anybody to pity them. I keep telling them; prove to everyone that you’re educated.*

This is supported by the system at BAL that praises academic achievement and musical talent. The parents perceive this as a way to alleviate any stigma that society would attach to the disability, and were thus supporting their children to be re-integrated into society.

## **F. Conclusions**

This chapter has addressed research question 3 on the impact of inclusive and exclusive practices on the social identities of visually impaired children by analysing the relationship between the children and their families and communities. Issues of belonging to a place or group emerged as central themes from the data gathered from students past and present. The findings illustrated that the children gradually developed a sense of attachment to the institution as a place where they fit with their disability. Their sense of belonging to people similar to themselves develops from their immediate family to primarily include their peer group of disabled persons. This is corroborated by the differential treatment they receive at home, whether positive or negative, from their parents, extended family and community. Furthermore, the strategies that the children developed to relate to their immediate communities were in the form of skilled achievements they learnt at BAL as visually impaired children, musical performance being one of them.

In the literature review on childhood in Chapter 2, it became clear that childhood is not uniform for all children, and that their 'childhoods' are influenced by a number of factors other than their chronological development. These factors were recognised as – the social context, inter-generational relations and social interactions. These all form the framework within which children 'make meaning' of their social worlds and their place within them.

Children living in boarding schools or residential centres such as BAL had different experiences from their siblings who continued to live at home. Their individual experiences of relating to their

parents are drastically changed, and the daily social contexts at the institution contained different interactions and relayed different messages to them and about them. This break from the home environment resulted in a different experience of childhood for the children living at BAL. The children realised that this dissimilar experience from the other children in their home environment was a result of their impairment, thus laying the grounds for a shift in 'belonging', for the formation of a solidarity group that is based on their shared experience of disability, and which they recognised as existing outside of their home environments. In a country like Lebanon, where much meaning is associated with family and geographical links, this significantly alters their own and others' sense of where they belong.

Looking into exclusion versus inclusion from the perspective of home, families and belonging addressed in this chapter, the data has indicated that the overall outcome of the residential system at BAL has been to directly or indirectly cultivate exclusion. The whole expert system that is set out by BAL is shaped by a medical model of disability that asserts that specialised care is required for the proper rehabilitation of the disabled child. This indirectly shut out the parents from their role as primary caregivers and child rearers, and contributed to the segregation and subsequent detachment of their children from their communities and wider society. Not only does this leave the children unprepared to re-integrate into society, but it also limits from any exposure of the children as they grow up to the wider society, thus hindering any possible change in public awareness and attitude towards visual impairment or disability. This links to the social isolation and segregation, the concept of disabling barriers (Finkelstein 1993). Children and alumni expressed their difficulties in leaving BAL to enter a society that presented disabling challenges in terms of attitudes, knowledge and practice.

The school has created an isolated setting, a sub-culture with a community of 'the blind' that the students clung to more and more as they grew older. This not only made it difficult for them to later find a place for themselves in society, it also made it difficult for them to fit back into their own

families. It socialised them into identifying themselves as disabled first and foremost, as members of an excluded group. Within this group, the children have slowly lost any motivation for resisting the system of power relations, which has extended from the school to their home surroundings.

This has contrasted with the data from inclusive settings where the analysis indicated that the 'expert' role was shared with teachers and parents. As argued in Chapter 4, in Foucauldian terms, partnership with parents had limited the 'clinical gaze' and power of professionals. Children had acclimatised to their own settings as all others, within their family and community. Foucault asserted that institutions are built for a specific purpose, and that terms may be to discipline its population before they can re-enter society. Raising disabled children outside a total institution carries the social meaning that they are not in need of 'reform', challenging that concept within the community.

## CHAPTER 7 – SELF & OTHERS • DISABLING IDENTITIES

### Introduction

This chapter addresses research question 3 investigating the impact of inclusive and exclusive practices on the social identities of children. The analyses in Chapters 5 and 6 have indicated that the practices of the institution have created symbolic relations that influence the children's sense of agency and belonging. This chapter presents an analysis of additional factors that impact on the children's social identities, such as valuing normalisation, devaluing the disability and present and future expectations, in addition to exploring how children manifest aspects of their identity formation as a disabled person. Based on the data, the argument here is that exclusionary practices of the institution and their influence on the home setting are socialising children into stereotypically inferior, disabled identities.

The previous three chapters have investigated the exclusive or inclusive ethos that is being created by policy and practice in Lebanon, and how that has influenced the status and links of children at the BAL school, as well as at home and with their families. This chapter focuses on the social construction of the children's identities within the parameters and arguments presented in the literature review (Chapters 1 and 2), including the management of stigma. It draws on symbolic interactionism which is influenced by the work of Goffman, who argued that 'the self' is produced by presentations in the social life, which are designed in response to perceptions of one's place in society.

From the point of view of the sociology of childhood, the children's management of their identities would also reflect how they are adapting to their role as an oppressed social group, and what modalities they are creating for their participation and agency within that role. Additionally, the

field of disability studies is relevant when analysing the social construction of the identities of people with disabilities. Within disability studies there is the individualised medical model of disability and the more recent social model of disability. There are critiques of both that have been reviewed in Chapter 1. The analysis of field notes and interviews in this chapter focuses on how the children are identifying themselves and their impairment within their social environment of the home and school through themes such as participation, normalisation, play, role-modelling, belonging and self-perceptions.

## **A. Normality & Normalisation**

When discussing normalisation in this chapter, reference is being made to the dictionary definition of the word – that is, the imposition of a standard – and not to the theory of normalisation and social role valorisation as theorised by Wolfensberger et al (Wolfensberger and Tullman 1982). Wolfensberger's assertion was that if culturally normative standards were used to value the role of a traditionally devalued member of society, then that would facilitate their integration and acceptance into society. The theories expand beyond this, with several sociological evaluation tools being developed, but they do not serve the purposes of our research to identify how children are being socialised into a particular role or identity. It is the researcher's standpoint that employing culturally normative standards and working with devalued individuals to excel and fit into them leans closer towards concepts of exclusion, normal versus abnormal, and once again lays the onus of change on the devalued individual rather than on the social environment.

It is argued here that the children are being socialised into stereotypically inferior identities, in other words, disabling identities. The distinction between this and "identity as a person with a disability" is that the former subscribes to a group identity constructed of discriminatory social

perceptions that are disabling to the person, whereas the latter is a process of self-reflection illustrated in stories of individual identity of persons who happen to have an impairment. From the varied data, themes of normalisation, denial and traditional disability stereotypes of weakness and inferiority emerged.

### ***Devaluing Disability***

A commonly held view is that people with impairments are incapable of performing up to 'normal' expectations. At the Lebanese School for the Blind (BAL), this was evident in terms of the expectations concerning the children's academic achievements.

In interviews with teachers and staff at the BAL, many opinions were expressed that reflected their low expectations of the students. Teachers, who were not trained to teach students with visual impairment, did not have high expectations for their students' academic performance. They were even sceptical of the scores that their students achieved on the official government examinations.

*Teacher 6: And all of this is assuming that they will graduate from here. I mean, we work our hearts out with some of these students to get ahead in any subject (but nothing...)*

*"Who knows how well qualified they will be – they are all passed in their government exams (baccalaureate) without the examiners even looking at their papers." (Yola)*

*"They are not doing any favours for the blind students with the formal exams, where we all know that all blind students definitely pass (no matter how they perform on the exam)." (Mr. Taha)*

As discussed earlier, BAL and the teachers consider fostering the children's academic progress as their main role, and as such place much emphasis on academic achievement. They consider the optimal course of action to normalise the disability and allow the children to re-integrate into

society with peers who are not visually impaired. Similarly, the achievement criteria focus on areas that are considered of high achievement to students who are not visually impaired, ignoring other measures of success and usefulness for persons with visual impairment.

*Teacher 6: Whatever they think of doing, they must go to university. There is no other way they can compete for the same jobs as sighted graduates.*

*“(BAL) prepared me to go to university and study Mathematics – which I then dropped because I realised that I couldn’t do anything with it, not teach or anything.” (Jamil’s interview)*

It appears that the driving force was to assist the students at BAL to academically overcompensate for their disability in order to be accepted by society. The overcompensation refers to directing the students to fields where success is highly regarded by society, but not necessarily of use to the person with visual impairment. It also refers to fields where the educational staff would not usually expect a student with visual impairment to succeed, thus any measure of accomplishment feeds into the ‘supercrip’ image; a triumphant superhuman achieving feats worthy of respect.

These same teachers, however, continue to highlight how disadvantaged the children are in the process of learning because of their visual impairment. They consistently expressed how children with visual impairment cannot learn in the same way as other students, which is true in terms of their need for alternative approaches and educational material, none of which were made available at BAL. As the teachers did not adopt any different teaching methods that could facilitate the process of teaching children with visual impairment, it appeared that their argument was based on the fact that without perfect sight, the children simply could not learn or take in as much as children without visual impairment.

*Teacher 2: (teaching a child with visual impairment is) absolutely different, a sighted child would understand quicker because he/she is using their sight.*

*Mr. Taha: Also, don't forget that the image (the picture) plays a big role (in learning), blind children can't keep up with the sighted children.*

*Teacher 6: It is totally different than teaching sighted students. I mean, 90% of what a student gets is from his vision, so the teaching had to be very different. I mean, I would be moving around and gesticulating, but that isn't doing any good. I teach English, and I talk Arabic in class, though I shouldn't, but there was just no other way.*

*Teacher 4: But you can't keep insisting that the child needs to be treated the same way, they require different type of work.*

The doubts of the staff and the administration regarding the children's ability to achieve academically also emerged from the back-up systems that had been set up. Academic performance was paralleled only by musical distinction, which was considered the other path that would be worthy of respect in society for visually impaired persons. Indeed the emphasis that was placed on music by the school administration was evident in the investment in musical equipment and training that exceeded what was made available for academic instruction or any other non-academic activity. Additionally, whereas academic success was seen as a stepping stone to higher education outside of BAL, and musical talent was similarly a path towards economic opportunities, the only option that BAL offered for failing in both is to direct the students to the handicrafts workshop.

*Omar (alumnus): At BAL, if you're not talented in music, you end up in the handicrafts workshop.*

*Jamil (alumnus): (the school) told others not to go to university – there's an inclination in all institutions for the blind that the students don't need to go beyond the Brevet (10th Grade). Instead, they would refer them to the handicrafts workshops or train them to work as phone operators.*

These limited options for students with visual impairment, reflected a conception on the administration's part that these were the only skills that were attainable for people with visual impairments. This slightly restricted vision was also reflected in the lack of any recreational

alternatives for students in residence at BAL. Aside from the television set in the main TV room, there were absolutely no other facilities for students to pass their time during their break sessions in the afternoon. All that was available was the space of the courtyard.

*Field Notes, 24/Oct/01: Pg. 20*

*I was sitting outside with Aida (one of the teachers) during one of the students' afternoon breaks. I had just arrived and it was not yet time for my session with the children. Aida had to attend to something else when I was once again mesmerized by the dull routine movement of the older children, boys and girls, arm-in-arm walking round and around in circles on the asphalt. When Aida returned, I just blurted out: "I just want to figure out why they do that – why do they just walk around?" Aida responded: "What else are they going to do?"*

This staff member's response represented the general opinion amongst the staff, that there was really no need to expand on or provide alternatives to what was already available, because there was only so much that visually impaired persons could do in any case. Whether this was born of the staff members' own opinions or was influenced by the system at the school was not clear, but either way the end result was this concept of limited abilities and possibilities for persons with visual impairment. This was probably the root of the supervisors' overprotective nature towards allowing the younger children to play in the courtyard or the outdoor playground equipment as described in Chapter 5, that they would not be able to avoid hurting themselves.

The school staff's attitude towards visual impairment was perhaps best represented in the distinction that they made between children with low vision and children who were completely visually impaired. Within the informal organisation of power among the students, the advantage was assigned to children with low vision. This was not challenged by the staff, and was additionally confirmed by them with errands and tasks being assigned to children with low-vision, frequently involving taking care of children who were blind. Through these actions, the staff were distinguishing between those who had some sight to those who had none, and were perceiving the former as being more capable and responsible for their actions.

*Field Notes, 24/Jan/2001, Pg 9*

*Children with low vision can be seen guiding their classmates and younger children to their classes when the bell rings ...*

*In the nursery class, when Yasmina, who is blind, wanted to go to the bathroom, Hussein, her classmate with low vision, was asked to lead her there.*

*Field Notes, 23/Oct/2001, Pg 18*

*Young Omar is a new addition to the Nursery class. He is taller than the others, and extremely thin and weak. As he would normally just stay seated wherever he is lead, one of the dormitory supervisors had asked two older boys with low vision to just walk him around. They did, and when they wanted to move on to something else, they would pass him onto Ayman or Riyad, who also had low-vision...*

*Tony, who has low-vision, is always called upon to fetch Leila, his classmate who is blind, and bring her to dinner and take her back to the older girls to take care of her.*

The students with low vision, whether they were younger or older, or even whether they were considered good performers academically or musically or not, were asked to run more errands than the students who were blind. In seeing the students with low vision as worthy of such responsibilities, and as these responsibilities usually involved a student who is blind, the staff were creating a pattern of care for those who were totally impaired by those who were less so. In other words, they were expressing their sense that the capacities of the children were diminished with the acuteness of their impairment.

In all of these actions and traits, the staff at BAL were devaluing the disability by attaching a host of inabilities to it – academically, recreationally, and socially. This emerged from their adoption of normalised criteria for behaviour and achievement as is indicated in their classroom methods, and in their expectations. Their standpoints were predominantly rooted in the medical model of disability in that their priority was to assist the children in overcoming their impairment in order to be accepted within the 'normal' standards. The absence of any recreational options or facilities suggested that the school administration did not consider these priorities or needs for persons with visual impairment who may not be able to appreciate them, and whose primary focus should be on

being accepted by society. The administration provided for this by focusing on the students' academic and musical training.

### *Passing for 'Normal' and Covering*

In Goffman's study of stigma (Goffman 1963), he referred to three strategies that are adopted by the disabled person in managing their stigmatised disability: 'passing' for normal and non-stigmatised; 'covering' the stigma so that it does not overwhelm social encounters; and 'withdrawal' from social activities with 'normals' altogether (Barnes, Mercer et al. 1999). In their daily interactions with their teachers or with the researcher, and in their interviews, the children at BAL seemed to adopt all three in different measures and in different contexts. This section will address the first two management strategies; 'passing' and 'covering'.

Analysis of the data showed that the children in their actions and interviews and from the parental reflections on their children, that these children are often attempting to pass for 'normal'. This was especially true of children with low vision who sensed a distinction between themselves and their blind peers, and who tried to use their limited vision to attempt tasks that could be achieved by their blind peers. In fact, these acts were sometimes meant to affirm the difference between them and these peers, thus presenting themselves as more 'normal'.

*"One of the boys with low vision is hunched over so close to his book that it appears as if he is reading Braille with his nose, but it turns out that he is reading it with his eyes." (Field Notes, 25/Jan/01: Pg 10)*

*Riyad is being taught Braille so that he has something to fall back on should he totally lose his sight, but I constantly saw him reading it with his eyes instead of his fingers.*

*Riyad's father: "I know! I see him reading it – and not with his fingers – and I just go "what are you doing?""*

*Riyad: "I hope to God I never need to use Braille alone because I read too slowly"*

Riyad is respectful and loyal to his friends, many of whom are blind, and would thus make light of comments regarding Braille or other implements that were specific to blind persons, such as the one above. This would be similar to a person with no physical impairment saying that they would probably be bad in a wheelchair because they would keep running into walls. Braille is Riyad's first language of instruction in the only school he has ever attended, and this comment represents a soft attempt to distance himself from it and, correspondingly, from the impairment. During his interview, he would try to explain different situations to me at the school by using phrases such as "These people (his peers) don't see" (Riyad's interview), implying that he feels he does. Quite often, these were also the students who were still seeking out medical procedures to restore the rest of their sight.

*Riyad: I had an operation in the summer (possibly for strabismus), and I feel I can see a little better.*

*His father did not think that these operations were making any difference to his son's sight.*

*Ayman's Mother: Once, Ayman and I were sitting on the balcony and he seemed deep in some thought. When I asked him what it was, he asked me if he could have an operation if someone would donate an eye, and he started crying. I told him that I had asked about it, and if donating an eye would work, I would have donated one of my own. But it doesn't work, it won't solve the problem.*

Other students with low vision also used passing as a strategy. They could be seen to be playing games that required sight – and here, reference is not being made to playing soccer or other ball games which most of the students seemed to manage quite well, but to card games and the like, using flat, unmarked cards. These games did not make allowances to include friends who were blind, who were often observed sitting just outside the 'game circle' while the others played.

*Field Notes, 1/Nov/01: Pg 21:*

*Outside the room, the boys were playing with their Pokemon disks and Jaafar and Kamal (both totally blind) were there, sitting just around the circle, totally left out. I came up to talk to the*

*children, asked them how they were playing the game, then said that, next time, we'll come up with a game that Jaafar and Kamal can play while the others are playing Pokemon. Jaafar and Kamal and the rest of the boys then started coming up with ways that they could adapt the Pokemon disks so that everyone could play.*

The children were clearly willing to involve their friends in these games, they had just not thought of the necessity of adapting games to include everyone when those with low-vision could play without any trouble. The children with low-vision probably found this a reaffirmation of their 'sighted' status, but they were also part of this larger group which included their blind friends. Perhaps they had not thought of ways to adapt their games because there were so few examples of such adaptations at the school for them to be inspired to do so. To some extent, it also implies that these children are striving to play these regular games and be like all other children.

This was again apparent in the preparations for the Student Council elections. In the weeks leading up to the elections, posters were hung up around the school campaigning for the different candidates, emulating the publicity campaigns of the local MP's (Field Notes, April 2001: Pg. 16). These were neither in Braille or any other tactile material – they were meant to be read, and those who could not read them would need to ask someone to do so for them. The posters were not particularly flashy or catchy and did not include much useful information, so it was not very clear how they served the election process. It appeared as if the students had gone to great lengths to execute the process as normally as possible, and had, in the meantime, excluded their severely visually impaired peers as most processes in the community do.

Aside from the children themselves, other staff or relatives in their lives were also encouraging them to appear as 'normal', whether directly or indirectly. These were mostly their siblings and family, who would take pride in how you could often not notice that their sibling or child had an impairment at all.

*Ayman's sister: If people were to spend time with him, they would realize that he is very normal but we need someone to appreciate that.*

*Yola is one of the dormitory supervisors who also has a brother at home who is blind. The following is an excerpt from notes taken after spending an afternoon with her.*

*She takes great pride in pointing out that you simply cannot tell that (her brother) is blind and recounts anecdotes of people waving at him or holding out their hands to shake his, not realising or forgetting that he cannot see them.*

*And then there are those who bring their friends or fiancées to the store to show them the blind guy.*

The siblings were equally aware of when people around them pointed, stared at or mocked their visually impaired sibling, and they were also managing the stigma by trying to have their sibling pass as 'normal'.

Attempts and motions for 'covering' the disability to stabilise social encounters were more noticeable among the students, and humour was a common tool. The students were constantly making jokes about their impairment, usually for the benefit of an audience who was not visually impaired. In fact, very few of the students referred to themselves as "blind" (*a`ama*) except in jest.

*Teacher 6: When I first started teaching here, I was so tensed up and so worried, but the students are the ones who helped me. They would keep cracking jokes (about their visual impairment), like "I had such a bad headache, I could no longer see", or bumping into me and saying "Oh, sorry Miss, I didn't see you there".*

*Field Notes, 18/Jan/01: Pg 6*

*In gym class, Josette – who is blind – puts on the blindfold (meant for the students with low vision) as well and yells out "I've become blind!!"*

A class role-play between two students in 4<sup>th</sup> grade was considered hilarious by their classmates because it depicted an incident when a taxi driver yelled out at a pedestrian "Can't you see?" and she replied, "No, I'm blind", which was met with roars of laughter from the children. What was more striking about the role-play was that it stalled after that line – neither of the students knew how the rest of the conversation might actually go (Field Notes, 11/Jan/01: Pg 3). The outburst of laughter may have also been a release in that the children turned the joke on the sighted driver, that they finally managed to call themselves 'blind' as a matter of fact, and not as a cause for sympathy.

The jokes about their impairment were a continuous means to try to make others feel more comfortable around them, and perhaps a defence mechanism to make the joke before somebody else did.

*Field Notes, 24/Jan/01: Pg 8*

*In Grade 6 – There are more jokes being made about being blind. They are asked to pick a grammatical element out of a sentence that has Sharon Stone in it. The boys ask about the sentence again and (the teacher) responds: "An amazing actress... if you saw her you'd fall over"*

*(One of the girls) retorts "Miss, he can't even see her and he's falling over, if he saw her he'd melt"*

These jokes, however, were not as common amongst the younger students who were struggling to think of themselves as visually impaired. Some, especially those with low-vision, had not come to terms with their sight loss at all and would probably have found jokes about their sight hurtful. Not unlike the older students, these children were overcompensating to overcome the disability of their impairment, and this habit extended to their social skills, where all their mannerisms were slightly exaggerated. They spoke louder, reacted impulsively, and went to great pains to entertain or attract attention by making jokes or coming up with witty put-downs. These were all typical of pre-teenagers, but they were exaggerated with this group. Furthermore, they never admitted that there was something that they could not know how to do, and would often try to prove to you that

they could do something. *"Honestly Miss. Shall I show you Miss? Shall I show you??"* Once again typical of children, but the persistence echoed a need to prove that they were 'normal'.

If they did admit to any type of incapacity, it was usually attached to elements or services that are lacking or beyond their control. In one of the older students' performances in their Christmas Show, they broached the issue of the rights of disabled people, but the disabled person that they depicted was physically disabled and used a wheelchair (Field Notes, Dec 00: Pg 1). The point that they wanted to drive home, that when they spoke of disability they were not just referring to visual impairment, was well received. But their arguments for the provisions and services that they felt disabled people deserved in order to overcome their disability were entrenched in the medical model outlook on disability. They were not rights-based, and not empowering. One explanation would be that they drew their world view from the vernacular used in the school, which demanded provisions that would allow the students to surmount their disabling impairment and fit into society.

In light of the attitudes among the staff and adults at BAL that devalued the disability of the students, their attempts to pass for normal or cover their disability may be a direct response to this. However, as family members were also involved in this process, it would appear that this defence mechanism or strategy to manage their stigma was for the benefit of people they had come into contact with outside of the school as well. Several examples illustrated the measures of denial, rejection or even mourning for their impairment, all of which fall into what the medical model of disability would assert as the process of dealing with loss (Shakespeare 1996). In all cases, the children were attempting to rectify what they now felt was a 'spoiled' identity, one that was deviant and a source of social stigma. Though one factor contributing to this stigma was the wider society and general social interactions, ascribing any part of the formation of this identity to the institution was only apparent when comparing these coping mechanisms with how children with visual impairment who had been included in regular schools, and continued to live at home, dealt with their impairments.

By a rather young age, the x children observed or interviewed who had been included in regular schooling illustrated very little shame or stigma associated with their disability. Quite to the contrary, they expressed their affirmation of being called 'blind' and, after a while, tired of and rejected being observed or studied.

*From Naji's home visit:*

*When I had first called to ask for this interview, the mother had asked that we meet somewhere outside the house as she did not want Naji to know about this. Naji had, in the last period, become annoyed with the slew of interviewers and students who were coming to write something about him. "What am I? A showcase??"*

*This is also the reason why his school no longer allowed such visitors to observe him in class.*

*(At the end of the interview, his mother) voiced her relief that it was not one of those interviews where the interviewer wanted to watch how Naji ate, or dressed, or did mundane things or the like.*

*When Naji performed (guitar) at the Presidential Palace, he met the First Lady (he won one of 2 prizes). When she asked him if there was anything he wanted, he said that he would like to see the Presidential Palace, and she took him for a tour and called in the President to see him. In the car afterwards, he told me that he really enjoyed meeting the First Lady, but mostly because when she called the President to come meet Naji, he heard her say to the President that Naji was blind. And Naji was pleased that she just said it as it was and didn't try to soften it up or make a big deal of it.*

*In preparation for an awareness raising photo exhibition where children were encouraged to take photographs of their days included in a regular school, Rida and Sara who were now at an UNRWA school apparently refused to take part in the exercise at first. Their reasons were: "We know why you're doing this, because we're blind. Well, there's nothing special about us being blind and we want you to stop pointing us out in that way."*

*(Personal Communication, UNRWA personnel, October 2002)*

These three children fell in the younger half of the 7 – 12 years age bracket under study, and yet had already rejected being labelled as 'disabled' without rejecting their impairment. They made no excuses for their impairment and continued to demand that they be treated with respect. Without

doubt, factors that facilitated this process for them were not only present at the school, but also at home where they continued to live, and in the community that they were not withdrawn from.

Whereas the children at BAL were working to achieve 'normality' in a detached setting, the included children were, for all purposes, living inclusively at home and at school with their impairment. These children's experiences and expressions of their disability could lead us to deduce that the institutionalised experience for the children at BAL; with all its components of staff, educational system, and family perceptions; was contributing to a sense of spoiled identity, and feeding into defence strategies and coping mechanisms focusing on 'passing' and 'covering'. Within such a small school population, there was little evidence of the students employing 'withdrawing' as one mechanism for handling their stigma during their school days. It could, however, be deduced that this was more widely adopted outside of the school, with the students who are integrated into regular high schools but do not mingle, and the alumni who return to BAL to live or work.

## **B. Self Perceptions, Aspirations & Role Models**

The literature review chapters discussed a number of elements that impinge on the child's sense of identity. James, Mayall, Lansdown and others illustrated the effects of language, culture, social perceptions, inter-generational relations and social interaction on the processes that children undertake to make meaning of their world and recognise their role within it. All of these elements appear in the analysis of the interview data to examine the process the children are undergoing in forming their self-identities and self-perceptions. This was certainly the case for children with visual impairment under study. As students in a school where their capacities were underrated due to the staff's devaluation of their disability, the children would naturally seek to be

acknowledged by attempting to do well within the skills that were highly rated at the school. They were simultaneously learning what skills gained them praise.

When setting up the interviews with the children, I had explained to them that I wanted to learn more about them and about how they dealt with things at home and at school. The first interview was with Maroun, who, upon hearing this explanation, immediately asked if I wanted to see how he writes. A Braille printer was brought to our small round table and he delicately explained how to feed in the paper, and printed my name for me to feel. (Maroun's interview)

Kinan, in his interview, did the same. This is what the children felt differentiated them, and what they felt they could teach me about how they dealt with things. No doubt this was a special skill in comparison to their siblings and family members at home who did not know Braille.

The children had started imagining themselves in the future. In their interviews and in their descriptions of what they would like to do when they grew up, the larger part of the children's dialogue reflected a paradox of their rejection or denial of their disability, as well as categorising themselves in traditional disabled roles. Historically in Lebanon and other Arab countries, children with visual impairments were trained to become priests and sheikhs. It was considered important to teach them the Bible and the Quran, and parents guided their visually impaired children to become priests or sheikhs as it was considered accessible employment that would socially compensate for their disability. In the last sixty years or so, they were also trained to become musicians, language teachers, telephone operators, or workers in handicrafts workshops. These became the socially expected lines of work for persons with visual impairment, and were propagated by institutions through vocational training that directed them to these professions. BAL is slightly different in its emphasis on academic study especially for the students in the elementary grades, but its focus on music has been previously illustrated, as well as the presence of its handicrafts workshop on hand for those who do not succeed academically or musically.

*Jaafar: "God knows (what I will be). Maybe teach English, they say that that would be a good thing for me."*

*Maroun: "A music teacher, or a priest."*

*Ahmad: "I want to become a sheikh."*

Perhaps the children had started sensing a level of inadequacy in comparison to non-disabled peers and their responses were seemingly in passive agreement with what others have suggested to them. This was slightly different for children with low-vision, who, as mentioned earlier, felt less disabled in the company of their blind peers, which assisted them in denying their disability. Their responses were typical of young children's dreams, or were plausible professions outside the group of sanctioned jobs for persons with visual impairment.

*Joseph: "I want to be an airplane pilot!"*

*Munira: "I want to go to university ... (and) become a lawyer."*

*Ayman: "I want to become a mechanic because I love cars."*

*Riyad (who loves computers): "I want to open up a computer company."*

The children's explorations of their potential future careers were also affected by the influential persons in their surrounding environment; either directly by their parents' and administration's advice, or indirectly by the staff's attitudes to their potential abilities, and the role models available to them through the visually impaired staff at the school.

The parents who were interviewed had high hopes for their children's futures. They expected that the children's time at BAL would enable them to overcome their disability and be able to pursue further studies or a career that would overcome society's attitude to their impairment. Education and high achievement was seen as key to reintegration and respect.

*Ahmad's father:*

*Most importantly, I don't want anybody to pity them. I keep telling them, prove to everyone that you're educated.*

*I want Ghina to go to university. She wants to study Psychology, but I would like her to study English Literature. I feel she can work with that, she can teach. I want her to have her status in society.*

*I would like Ahmad to become a musician; I feel it is a good profession*

*Upon mentioning that Ahmad said he wanted to be a sheikh, the grandmother responded:*

*That is probably because of me, I would like him to be a sheikh.*

*Ayman's mother: I wanted him to be an eye doctor, or a mechanic because he really likes cars.*

The parents, and grandparents, are naturally looking out for what they felt might be in the best interests of their children, but aside from an overambitious desire for a child with low-vision to become an ophthalmologist, they all subscribed to the traditional professions assigned to persons with visual impairment. Ayman's mother, in her response, presents hints of denial of her son's impairment, which probably assists her son in doing the same, as indicated in his ongoing hope and quest for medical procedures to eliminate his impairment.

The BAL staff views concerning the children's futures were derived from their experiences with older students at the school. The importance attached to academic studies and music was tangible in that they were the only areas for which they received the highest recognition, and were afforded informal power, by the director and by the staff. The proximity of the handicrafts workshop and the workers and telephone operators who shared residence with the students also alerted them to what their other possibilities were should they not succeed academically or musically.

*Omar (alumnus): the handicrafts workshop has generally been for... school dropouts (from BAL or elsewhere) or those who don't like education... At BAL, if you're not talented in music, you end up in the handicrafts workshop.*

The educational staff was never observed giving career counselling advice, but their opinions and thoughts as to the students' future prospects probably filtered into their attitudes and instruction in class. In all fairness, these views were not necessarily their personal opinions as much as they represented a synthesis of where they thought society would accept visually impaired employees.

*There was a long pause among the teachers in their group interview when they were asked what career choices they thought their students would have. Finally, there were only a few suggestions...*

*Teacher 6: I only see them working as phone operators (which others – mainly the blind teachers – argued with)*

*Teacher 7: they are going to have a lot of better job opportunities because everything is computerized now. I know someone who is working as a translator, someone is working at ESCWA. There are opportunities. Which would hopefully improve in the future.*

*Teacher 6: They could go into computers*

The teachers did not seem to have given the students' future much thought beyond what has been set out by the administration and society in general, and remained sceptical of affirmative action measures that had started to appear as a result of Law 220/2000.

*Teacher 3: Yes, but look at how it's (Law 220) being implemented in some places – blind people are getting paid (employed) without being given a job to do. It's just as bad as begging.*

These are the same teachers who barely expected that their students would graduate. For those who would the teachers did not seem particularly hopeful of the opportunities that would be made available to them.

*Mr. Taha (blind teacher): You don't think of what you want, you just think that you need to work. I know two people who had Master's degrees, and now they're just working as phone operators.*

The visually impaired teachers at the school mainly taught music or languages; Braille, English or Arabic; with the exception of one who runs the computer classes. They constituted the students' immediate professional role models, and were respected in accordance with the higher importance ascribed to the educational staff at BAL. It was these very same role models, some of whom were BAL alumni, who had returned to teach at their alma mater. Not only did they follow in a traditional profession, but they also preferred to pursue it in a special school. This contributed to the children's sense of belonging at BAL, which will be discussed further in the following section, but also reaffirmed some of the opinions that had been expressed to them regarding the limitations of their future opportunities.

Marriage seemed to preoccupy the girls more than the boys. Specifically in this area, the students looked to the visually impaired staff for clues as to what they might expect. Of all the visually impaired staff at BAL, only two of the teachers were married, one of whom, a female, was married the year that the data collection was conducted. All the other visually impaired staff, visitors and alumni that the students came into contact with remained unmarried.

*Yola (dormitory supervisor):*

*She mentions that the girls at (BAL) are always thinking of when they get married. Thoughts similar to those that would occupy the minds of any average teenager. She feels that all the possible obstacles or challenges in doing something like that doesn't occur to them, and they raise the issue whenever they have an outside speaker "Why are our chances to get married so low when they are not for boys?"*

*People also urge Yola to find a bride for her brother. She feels that she cannot pass such a burden on to somebody else.*

Nobody seems to have provided a clear response to the girls' persistent questions, almost as if, as indicated by Yola above, they should recognise the clear hindrances. In the children's interviews, the two girls in the sample group were the only ones to bring up the issue of marriage, but with an interesting condition – *“I would like to get married, to someone who is not blind”* (Samia). When I enquired why they specified this quality in their potential spouse, their non-verbal retort indicated that it should be intensely obvious; the girls wanted to marry out of the discriminatory perception of their disability, this was one way to break the endless cycle and provide them with a less limited life in the mainstream.

All the guidance and information that the children received regarding their future role in the society's economy fell within the existing system that had made allowances for persons with visual impairment in a few professions. When opinions emerged to challenge this system, they were usually unrealistic or overambitious and rooted in a denial of the disability. When being presented with what to expect in the job market, either directly or through their own observations, the children were presented with a group-specific category of jobs. These were the fields that you may be able to pursue as a visually impaired person. The focus was on the impairment and what that would allow them to do, rather than on any individual basis of potential, talent or inclination.

These restrictions overflowed into future social prospects of marriage, where they were also taught to curb their expectations because of their disability. This was especially pertinent to the girls, not necessarily in terms of finding someone who would love them and marry them, but that there would be great social resistance to such an occurrence. While the system that had placed them at BAL is coaxing them to defy their disability and prove themselves to society, it was concurrently guiding them into pigeon-holed options due to what was socially perceived as appropriate for their inabilities and inadequacies.

## C. Belonging to a Group / Identifying with the Disability

Many of the issues and themes that have been analysed and discussed thus far influence the children's sense of belonging to a group and identifying with their disability. This did not only emanate from their need to associate or identify with a group, but was also affected by external factors such as the perceptions imposed upon them by the school administration and staff, their segregation within an enclosed environment away from their homes, their parents' views and involvement and the discriminatory attitudes that they faced in the outside community. With time, the children found strength and understanding in their visually impaired peers, and thus commenced to feel they belonged to this social group.

Their sense of belonging to this group was also linked to the school itself, as was observed in their growing attachment to remaining in the school on weekends, and returning there after graduating. Belonging to this group was thus, to some extent, one facet of the third strategy proposed by Goffman for managing stigma; withdrawal. All of the children perceived themselves as different enough to warrant them living at BAL. They felt that they belonged at BAL as disabled and different children who were *"all the same here"* (Kamal), and because of their fear of being in a regular school. Children who had attended a regular school before coming to BAL, described their school only as having not been *"for blind children"* (Munira, Kinan, Adel – children with low vision), or as one where *"there were all types of people ... but I was the only one who was blind"* (Maroun). Being in a special school such as BAL actually provided the students with a space where their impairment almost became invisible.

*Abed (alumnus): At (BAL), you don't feel like your lacking/missing something.*

They also feared being outside of BAL because they simply would not fit in, and they would lose whatever status they had gained within the BAL community.

*Riyad: "But it would be difficult to go to a regular school, because of the atmosphere there and my friends being here. It has nothing to do with the actual classes or studies, I just wouldn't want to leave (BAL)"*

*Abed (alumnus): "What can a blind child play (in the neighbourhood)? He will always be segregated/excluded, will always be clinging to his family and parents, he won't play with the kids in the neighbourhood. I remember when I was young I used to hold onto my mother's dress and follow her everywhere."*

*"I can't explain why it would be harder at an inclusive school ... you know, you'll always trip on a step, or someone might trip you..."*

Thus their reservations were not only that they would not fit in the outside world, but that they would also be subjects of abuse, and that the community would not understand them or know how to deal with them. Their fear of being segregated or excluded from their neighbourhood led them to a segregated setting at BAL.

This sense of being 'out of place' extended to their homes as well. As discussed in Chapter 6, the children became acutely aware of their sense of difference in comparison to their siblings who continued to live at home. The parents continuously stated how pleased they were with BAL and how the staff had helped them with different issues regarding their children's upbringing. These were all statements that were made in front of the children, who slowly internalised the important role that the school was playing.

*Ayman's mother:*

*It wasn't easy for me to send him. But Ayman was having a tough time at home, he wasn't accepting his predicament. He was always angry or nervous. It all changed when he went to (BAL), he calmed down considerably.*

*Riyad's father: We are really happy about the school in general, we haven't had any trouble ever since we sent Riyad there.*

*Ahmad's father: It's different at (BAL) than if they were going to school here. You can see the difference, they're disciplined to be polite, their social interactions are different (better).*

The mutual affection between children and parents was clearly expressed, but the estrangement related more to a faint understanding of what the children did and how they were dealing with their impairment. Moreover, the parents' non-challenging and dependent relationship on the BAL administration bestowed more power to the latter regarding decisions concerning the children, and the children were aware of this. Though the children struggled to create links between their school and homes, these efforts eventually petered out as the gap between their two lives became wider, and as their sense of belonging at BAL grew.

*Ruba: At the beginning, I wanted to go home all the time. Towards the end, I didn't want to leave (BAL) any more.*

*Abed: When I was younger, I didn't used to want to go home.*

The school administration and educational staff also contributed to drawing out the contours of this group. As discussed in Chapter 5, the school administration had adopted an exclusive ethos in which it viewed the students as a homogeneous group due to their shared impairment. This applied to the educational approaches and the control of the social space. It had created this enclosed space that was detached from the surrounding environment, and had acted in a specialised, expert role that distanced the parents from their children's daily lives for reasons of expertise and economics. These children were living different experiences from their siblings and family, which was only partly due to their impairment, and partly due to their residence and attendance at BAL.

All things considered, the students understood that their best option was to be to be at BAL. As students in this enclosed setting, they also coveted the opportunity to obtain the high grades that

would allow them to be integrated into a regular school at high school level. However, it emerged from the interviews with present and past students of BAL that this was not a comfortable move for them, but was probably desired because it was a sign of achievement that earned high praise from the school administration, and naturally the parents.

*Ruba (alumnus): In the last few years, I was integrated in the high school in Kfarchima ... Us blind students would also always stay together. The others couldn't really mingle with us.*

*Omar (alumnus): Making friends at the regular school didn't come naturally to everyone ... Some of the (blind students) stayed alone at the regular school.*

*Ghina (currently integrated in a regular high school): It was just hard at the beginning, for a week or so, but then I got used to. They're all very helpful at the school. But some of my friends are still finding it hard to be there.*

*Not just being in a new school, it's very different than here (at BAL). Here you're among people like you who are also blind, and it's much different being around students who can also see...*

This first foray into the outside world confirmed to the students that they were extremely different from the others and that they belonged at BAL. The special treatment that they received, whether negative in terms of minimal socialising, or positive in terms of examinations being sent to BAL in order to be printed in Braille for the student to execute in the afternoon with little supervision and no time limit; was an additional line distinguishing and separating the students from their peers who were not visually impaired. This was one additional factor contributing to the students identifying with their own social group, one in which they shared similar experiences due to their visual impairment.

As mentioned earlier, one alumnus likened his time at BAL to that of being in prison for a period of time, in the sense of being cut off from the outside world and belonging totally to the institution. The lasting effects of this sense of not belonging anywhere else other than BAL was observed in alumni who returned to the school, either to work or to continue studying.

*Field Notes, 13/Jan/2001, Pg 4:*

*Another one (girl in the over -20 years old classroom) has been through the whole educational process somewhere else, but found it hard to step out into the 'world' and has come here to take classes in English, computer and handicrafts.*

*Omar (alumnus): The handicrafts workshop has generally been for ... people who graduate and live far away (and don't want to go back to their villages)*

A number of the visually impaired staff at BAL were alumni of the school. Aside from a few who were teachers, others returned to live there and took on miscellaneous tasks as support staff. Notwithstanding their own experiences, their presence at the school with the full knowledge that they were alumni presented another indication to the children that they all belonged to this same group that was not connected through an educational experience, but through their impairment.

## **D. Conclusions**

This chapter has addressed research question 3 on the impact of inclusive and exclusive practices on the children's social identities by exploring themes such as participation, normalisation, play, role-modelling, belonging and self-perceptions. The argument in this chapter is that disabled children learning in segregated residential institutions are being socialised into disabled identities.

The findings show that the students at BAL have identified themselves with a group of their peers who share their impairment. This has been amplified by their presence in a segregated setting in two distinct ways. On the one hand, this setting has protected them from the social stereotyping and discriminatory behaviour of their home neighbourhoods, and from what appears to them as the lack of understanding and qualification of their families; they do not, after all, come from families who share their experience in terms of their impairment. On the other hand, within this

enclosed setting, the children were subjected to an administrative system and perceptions and attitudes of the staff, that treated the students as a homogeneous group. Moreover, these experts were assisting them in dealing with their disability, and yet were predominantly negative in their evaluation of the students' capabilities due to their impairment. The older students, the returning alumni, and the visually impaired staff and teachers were their only available role models, and their experiences were not empowering. There was no challenging case for change due to their own conformity to the existing social attitudes, and the reaffirmation that this segregated institution is where they belong.

The children had been socialised into a spoiled identity, one that had become so because of its deviance from what would be considered 'normal'. The stigma that they carried was illustrated in the strategies that they adopted to manage it, in their quest for normalisation, for passing as normal and for covering their disability, which they felt was considered the most pertinent part of their identity to other people they interacted with. The aim of these management strategies was to be socially accepted.

The loss or diminishment of their sight was also associated with a sense of inferiority and inadequacy to perform, be industrious, or to obtain a productive place in society's economy. This was, after all, considered the optimal path towards social acceptance and re-integration. Yet throughout this process, they were being guided into professions that have been traditionally socially accepted for persons with visual impairment, continuing their categorisation and assignment to this disabled group, as their only future means for economic gain. They were taught that they would always be inferior to others who pursued other fields of work, or had a wider choice of doing so, and that their abilities would always be insufficient to engage in other professions. The basis for this was not their own capacities or potential, but the social obstacles that they would face.

Throughout these experiences, the children encountered social discrimination in their home communities, expressed a sense of progressive estrangement from their home environment, and were subject to a specialised institutional system that perceived them as a homogeneous group. In the process, a solidarity grew out of these shared concerns and developed into a sense of belonging to this social group. This group passively took on the traditional roles of persons with visual impairment; such as expecting charity, taking on occupations traditionally assigned to visually impaired persons, relating to those in their surrounding environment through musical performance, and merely retreating from games or settings that required sight. The group is defined by its disability, by its deviation from standard mould, not by any other traits of its individual members. The students internalised this and were being socialised into this disabled identity, and not into an identity of an individual person with a disability.

To quote Weeks, *"identity is about belonging, about what you have in common with some other people and what differentiates you from others. At its most basic, it gives you a sense of personal location, the stable core to your individuality."* (Weeks cited in (Shakespeare 1996). Social constructionism plays a prominent role where inputs from all social actors in the children's social life portray them as spoiled or deficient. These attitudes are reflected in decisions that are made about their lives, such as sending them to a segregated special school, in social interactions of avoidance or derision in their home community, and in the control and sympathy that they are subjected to at their special school. . Wherein all of these social interactions treat them as commonly disabled, as different from those in their family and social circles, the children find their personal individuality within a group of their disabled peers.

The analysis in this chapter has shown that disabled children attending institutions were managing stigmas and were being socialised into disabled identities. In addition to the findings drawn from the data at the institution, the links between institutionalisation and spoiled identities were further emphasized as such stigmatized identities were not evident or manifested in any of the visually

impaired children who were included in regular education, indicating that different social values were being attached to their impairment, and it is these values that have been the primary influences on the children's identity formation.

## CHAPTER 8 – CONCLUSIONS

This thesis has investigated the influence of social policy and practice on the social construction of disabling identities of severely visually impaired children in Lebanon. It has done so by exploring the philosophical underpinnings of the recent 'Rights & Access for Disabled Persons' law, Law 220, passed by government in 2000, as well as the social interactions and positioning of children in their segregated school and home environment.

This is the first study in Lebanon to engage disabled children as primary sources of data, and the only one to date to systematically address the roots and routes of these identities for children. This concluding chapter of the thesis discusses some methodological issues and also sets out the original empirical and theoretical contributions to knowledge of this thesis. The research questions were:

1. To what extent do current policies and practices in Lebanon foster inclusion versus exclusion of disabled children under 12 as part of a rights based approach?
2. What are the mechanisms and processes that allow the voices of severely visually impaired children in residential institutions to be heard?
3. How do elements of inclusive and exclusive practices impact on the social identities of severely visually impaired children in Lebanon?

## **A. Methodological Issues – Strengths and Limitations**

As discussed in Chapter 3 on Research Methods, an organizational ethnography was considered an appropriate methodology for this research study on the social identities of visually impaired children in Lebanon. It is the first study of disabled children in the Arab region to employ an ethnographic approach and was a powerful method through which to learn about practice and experience.

Nurturing trust among the school community greatly facilitated data collection during the stages of participant observation, as well as during the home visits and interviews. The data collection was undertaken during two periods separated by the summer vacation and this reinforced the nature of my presence as relating purely to research, since no changes had been introduced at the start of the new academic year. This was important for ethical reasons, to avoid raising expectations, and as an affirmation that responses to the interviews that would take place in the second data collection period were not biased by any subtle expectations of administrative change.

Becoming a part of the disabled children's social circle for the duration of the fieldwork period also influenced the analysis of Law 220. In addition to the analysis of the law as a legal document, doing so after having started ethnographic data collection, added another dimension namely an awareness of user perspectives. How would this be understood or used by the parents of BAL students? This user perspective was further explored in the interviews with parents and disabled persons who were active in the advocacy process to obtain representative views from across the spectrum of primary stakeholders affected by the law.

Throughout the data collection and analysis, I was working in the fields of children's rights and disability issues in Lebanon. In some ways this greatly contributed to the research process. It frequently offered additional data relevant to the aims of this research, as well as variant

perspectives in the analysis of the data, which could not have been raised or discussed outside of work settings. However, my own work was in the field of developing inclusive approaches, and this contrasted in terms of focus and values with the approach and ethos of the institution where I conducted most of the fieldwork. This meant that I needed to set aside my own positioning, and relate as openly as possible with staff and students, without being judgemental. The staff was aware of the nature of my work and would occasionally discuss inclusion issues with me, indicating in these conversations that they considered their work on integrating older students in regular schools as inclusion. These discourses contributed to neutralising our different positions on the topic and facilitated frank exchanges.

The research methodology had several limitations. Conducting a case study using an organizational ethnographic approach focused the data collection on one specific setting, the BAL school. This meant that the size of the sample in terms of students, staff and parents was small within the targeted age group.

The study did not focus on gender issues in depth. Lebanon is a more liberal country than a number of other Arab countries, but it is still a very gendered society. Aside from gender distinctions of ascribed status among the students (Chapter 5), and links to the neighbourhood and community (Chapter 7), very few other gender issues appeared. This was in part due to the young age of the children studied but was also related to the fact that there were only three girls at BAL out of the fifteen boarding students ranging in age between 7 – 12 years. Although this small percentage could in itself point to a gender issue in terms of who is sent away to residential schools, it was not possible to explore this further within the scope of the adopted research method.

The study population contained one student who was a Palestinian refugee. While this is reflective of the small percentage of Palestinian refugees in Lebanon (around 10 – 11%), it was

insufficient to draw out any issues specifically related to refugee status in terms of any additional social discrimination of disabled refugee children. This was further exacerbated by the BAL's policy to forbid talk of any political issues on school grounds, and this was considered a political issue.

As indicated in the description of the student population at BAL, around one quarter of the students were not boarders and returned home at the end of the day. These students were not included in the study population as the Administration did not grant me access to any free time with the children during the school day. It was apparent from the children in the study group, who were close friends with some of the day students, that there was a complete separation between the day students and boarders outside of the school. They did not visit each other's homes or meet outside of the school, which was probably brought on by geographical distances as boarding students who lived in the same town did occasionally visit each other at home. This separation would also imply potential differences in the experiences of these day students at BAL which are not represented in this thesis.

It was quite apparent early on that institutions such as BAL catered to the needs of children and families of predominantly low socio-economic status. One clear reason for this was the confirmation of a leading ophthalmologist in Lebanon that the prevailing causes of visual impairment in children – consanguinity, lacking or incorrect pre- and post-natal care, and surgeries undertaken by unspecialised generalists – existed mainly among poorer communities. It could thus be said that the research was addressing issues that were relevant to the majority of visually impaired children in Lebanon. It could not, however, address or learn about issues pertaining to visually impaired children and families of high socio-economic status, who were either being included through their families' initiative and expense, or else were sent abroad. However, the attitude of the parents of children attending the institution, which was in the main uncritical, grateful and passive (Chapter 5), may have been influenced by their socio-economic status, lack of other

options and realisation that this institution was giving their children enhanced life chances. These limitations simultaneously offer opportunities for further subsequent research in this area.

## **B. Main Empirical Findings**

The first research question was: To what extent do current policies and practices in Lebanon foster inclusion versus exclusion of disabled children under 12 as part of a rights based approach?

This is addressed in Chapter 4 (Lebanese Policy Context) and parts of Chapter 5 (Exclusion versus Inclusion). The findings have shown that although current legislation and policy in Lebanon are based on rights-based perspectives, the content of the law continues to interpret this within segregated notions of equality. That is, the rights violations towards disabled persons that existed in Lebanese policy are being rectified by creating separate parallels for disabled persons. These parallels consist of measures that have adopted a social model approach by adapting disabling barriers and creating allowances in health, education, employment, housing, recreation and transport, but, as parallels, they do not make it a requirement that any of the mainstream service provision become inclusive for all. Whereas the law subscribed to the thrust of the social model to bring disabled people into society, it only managed to create a concentric circle for them on its fringe. This reflects the perception of disability as a general misfortune which policymakers have responded to by broadening the outreach of governmental services (Donoghue 2003).

Aside from specific interventions on language and labelling spearheaded by civil society, and the definition of a disabled person in Law 220 addressing disabling barriers, the content of the law reverts to prevailing understandings of disabled persons and their support. Those who capitalise on the potential opportunities within the law's delineation of rights in specific realms, and challenge the segregation of its implementation, do so individually, mirroring a medical model outlook that

places the burden of 'fitting in' on the disabled person. Therefore, the content of the law did not challenge socially constructed views of disability or stereotypes of incapacity. Additionally, the content of the law did not include mechanisms to support its implementation, within ministries and governmental decision making processes, and has thus had little influence on adapting or changing the system of service provision or practice.

The findings indicate that these measures also do not actually reach all disabled persons with a continued low representation of Disability Card holders compared to the estimated number of disabled persons in Lebanon. The representation of children was also found to be lacking, both in the legislation as well as in practical outreach. It addresses them indirectly through parents, many of whom were found not to have heard about the law or were unaware of what it entailed. As parents whose children attended BAL, where the Psychosocial Coordinator took charge of all issues related to the Disability Card, it reflected how, in practice, the current implementation of the law enhanced the role of professionals in controlling its execution. This influenced the parents' perceived restrictions in addressing the Administration at BAL or questioning its decisions. The Administration upheld an 'expert' role with parents and children, mirroring the medical model of disability. This was additionally emphasized by the Administration's knowledge and control of issues pertaining to financial sponsorship and subsidies from private donors, MoSA and UNRWA.

In the study of the institution in Chapter 5, the institution was found to propagate an exclusionary ethos, as evidenced by the findings. It was physically cut off from its surroundings, which were in themselves remote. On the inside, access to the school grounds was circumscribed both spatially and temporally, a regimentation that reflected Goffman's description of total institutions (Goffman 1961). Areas were assigned specific purposes, and the purpose of BAL was to contain visually impaired children, a view voiced by the children themselves who felt they belonged there. The space and the students' movement within it were also designed to maintain a level of surveillance

by staff at all times, enforcing hegemonic power relations that are quite contrary to the standards of inclusion.

At the time of the data collection, the school had few measures of inclusive adaptation. It attended to the needs of the visually impaired students only by providing the class texts in Braille or large print. The curriculum was not otherwise adapted in terms of teaching aids or methods to assist the students' learning. Teachers themselves were widely not trained in general education or special education techniques.

Central to the children's lives at the school was the value system attached to ascribed and achieved status. Children assigned a higher ascribed status to children who were older (age), boys (gender) with low vision and not severely visually impaired. These discriminatory lines that existed in society were reflected among the students, including discrimination against disability. Staff played a more active role in promoting achieved status, specifically in academic or musical achievement, the former being a general expectation of all students in Lebanon, and the latter a traditional expectation of visually impaired children. Both sets of expectations guided students towards socially acceptable goals in order to be accepted and praised. In short, the system was not challenging any of the long-held assumptions about disabled persons, nor was it introducing rights-based principles that seek to promote the individual potential of disabled children.

Overall, the empirical findings have shown that current policy and its ensuing practices propagated exclusion of disabled children in Lebanon. There were no indications that the policy had introduced rights based systems of accountability and involving stakeholders, and the refusal of governmental agencies to activate Law 220 as related to each of their briefs demonstrated a rejection of inclusive, rights-based changes to their mechanisms. It can be deduced that Law 220 effectively enhanced existing systems of control or created similar sub-systems. Additionally, as evidenced by the exclusionary nature of institutional practice, it can be argued that the law failed to

address the decentralised nodes of these power relations. Expert knowledge continued to be enhanced as a constraining authority.

This data and analysis have shown that adopting a rights based approach in legislation is not sufficient to bring about changes towards inclusion in policy and practice. This is further diminished by adopting a social model approach focusing on disabling barriers. The analysis has indicated that, at the level of practice, the most influential factor was the 'expert' status maintained by professionals, which was not immediately transformed by inclusive legislation on its own.

This is particularly relevant in the Arab world where disability laws are currently being developed and adopted. These emerge in similar contexts where services for disabled persons are predominantly specialised and segregatory or separate. In countries such as Bahrain or Syria, disability laws are being modelled after Lebanon's 'Rights & Access for the Disabled' law, which means that they too will be susceptible to the challenges that have been faced in putting this law into practice which have been highlighted here.

The second research question was: What are the mechanisms and processes that allow the voices of severely visually impaired children in residential institutions to be heard?

This is addressed in Chapter 5 (Exclusion versus Inclusion) and Chapter 6 (Out of Place) where mechanisms for severely visually impaired children to voice their views was explored in depth in the institution, and home environment.

The ethnographic data gathered at the institution demonstrated the absence of any effective formal mechanisms through which the students could have their voices heard. The decision-making structure was quite hierarchical with absolute control exercised by the Director. The

student council did not represent children under 14 years, and the 'adaptation classes' that were held with the Director of the institution were similarly exclusively for higher classes. Children were observed to capitalise on their achieved status, where possible, to influence a change or voice their opinions to the staff or Director. In addition, children with high ascribed status, in line with the criteria listed earlier which were directly or indirectly promoted by the staff, were also seen to manipulate that in order to get their way. In both instances, the scope of such child-initiated changes was mostly limited to immediate and temporary changes, usually relating to manoeuvring around the time-space schedule. The children had otherwise no opportunities to voice their opinions, certainly not those who had low status and they mostly internalised the values of the institution and expressed little resistance. This directly points to the need for establishing mechanisms for their participation, both as a means for respecting their rights to do so, as well as creating the space within which they can explore their individual identities vis-à-vis the values of the institution and the society at large. This is additionally relevant to these children who come from low socioeconomic backgrounds, a factor which also disempowered their parents within this context.

The effect of this centralised system of control on parents was discussed in Chapter 6. Though the parents' committee was by definition their platform for participating in the institution, its role was quite limited and symbolic, with representatives of the Administration attending and facilitating the committee's meetings. Additionally, the Administration's self-assigned task of attending to financial issues, as described earlier, and the School's technical inputs into educating and rearing visually impaired children also positioned the parents as receivers of care. In such a position, parents were unwilling to challenge the Administration and risk a loss in the support that it was offering them and their children. The parents had, in many ways left decisions concerning the education and welfare of their children to the Administration. These ranged from the medical and educational to the behavioural, all of which were elements of the surveillance system the School

employed through its follow up procedure with parents. Such a surrendering of parental duties to an entity outside the extended family is uncommon in Lebanese society.

It is argued here that children and parents were disempowered and disciplined into behaviour that did not challenge or defy the institution, and that represented a “crystallized” form of power (Prado 2000): 71). The impact of the changed parental roles was evident in the children’s narratives. In terms of exercising resistance and participation within the School, the children at this young age perhaps realised that they would not be supported or protected by their parents, or just wanted to please those who were caring for them.

The third research question was: How do elements of inclusive and exclusive practices impact on the social identities of severely visually impaired children in Lebanon?

This is addressed in Chapter 6 (Out of Place) and Chapter 7 (Self & Others). Despite expressions of strong emotional relationships with immediate family members, the findings indicated that there was a clear detachment for the children between their lives at BAL and at home, and children within the study group, that is 12 years old or younger, were going to some lengths to maintain or recreate rapport with their families.

Alumni expressed their inability to find their place within their families after a few years at BAL. Aside from a resulting disjointed relationship with their families, they had also become unaccustomed to dealing with the community in their home neighbourhood, and vice versa. This varied slightly for children whose families lived in more rural and smaller close knit communities, where they could move around and socialise more easily, but this setting remained quite different from what they were used to at BAL and thus also hindered their re-integration.

Overall, the children could best relate to their families and communities by attempting to 'normalise' their actions and achievements. This only served to confirm their disability and their difference from 'the norm'.

This dichotomy of their experiences inside and outside BAL reinforced their belonging to a similarly disabled peer group, and perceiving that group as existing mainly at BAL. The School had created an isolated sub-culture of 'the blind' that the students clung to more and more as they grew older. It was the place or group where they felt that they belonged because it was where they felt they were accepted; in a group that shared their experience of difference and discrimination. Their experience of physical segregation has led to self-initiated social segregation. The findings in Chapter 7 demonstrate how these many factors were internalised in the children's self-perception and identity formation.

It was shown that the children were stratified at the school according to ascribed and achieved status. The criteria for this were derived from a perspective that devalued the disability; that severely visually impaired children were incapable of doing as much as children with low vision, and that they were all expected to grasp the educational curriculum by themselves without the assistance of any adjustments to the teaching methods. There were explicitly expressed expectations of low achievement from teachers and staff.

The children exhibited strategies for "passing", "covering" and "withdrawing" which can only be considered strategies for managing stigma (Goffman 1963). That is, the children were employing social ploys to diminish their disability by attempting to pass for normal, or by covering it up. When these strategies failed, they withdrew from the social setting altogether, as evidenced by their self-imposed social segregation.

The teachers did not have very high aspirations for the children's futures. Severely visually impaired children aspired to occupations traditionally assigned to visually impaired persons, and those with low vision expressed dreams of occupations in a manner typical of young children. Their parents subscribed to the expectations of the School and society, and generally guided their children to traditional occupations.

The role models that the children had in visually impaired adults at BAL did not challenge their perceptions of disability as stigma, or the perceived capabilities of visually impaired persons. The visually impaired adults at BAL were in jobs that were considered acceptable for visually impaired people, and often employed the same strategies for managing stigma.

These various elements contributed to socialising the children into a stereotypically 'spoiled' disabled identity, rather than an identity of a 'person with a disability'. This seemed to contrast with the limited findings from included children, who at the same age, exhibited few signs of stigma, at home or at school. Further research is required to fully validate this.

In conclusion, these empirical findings have contributed to understanding and knowledge of disability legislation, policy and practice in a number of ways. They have shown that rights based legislation cannot impose inclusive changes in policy and practice without mechanisms and incentives in place for implementation. In the absence of such change, practices remain predominantly exclusionary, with no effective mechanisms for the meaningful participation of parents or children, eventually socialising the children into disabled identities. This has relevance for other countries in the Middle East who have adopted Law 220 as a model for their own legislation, and other countries that are formulating similar legislation. In order to change provision and practice, a full implementation programme has to be in place with participation of

stakeholders, activists and professionals in partnership. Without this, the gap between the rhetoric of the legislation and policy and the provision and practice will only be bridged with difficulty and very slowly as is the case in Lebanon.

The findings have shown that children 8 - 12 years of age were not exhibiting any noticeable resistance to the systems of control, and had adopted the discriminatory values relating to disability, exhibited around them. This may change later on in their lives although the data does not extend to any possible changes in their later years. Some of the interviewed alumni expressed some resistance to these values later in life, while others did not and continued to return to the institution as visitors or friends. This would indicate that it is of particular importance for young children that there are formal mechanisms in place for them to express their views.

### **C. Main Theoretical and Empirical Contributions to Knowledge**

This thesis makes an original empirical contribution to knowledge through its methodological approach within Lebanon as an organisational ethnography study of children and staff within an institution for visually impaired children. The thesis also makes an original contribution to empirical knowledge by this detailed analysis of legislation and the lack of its implementation at the policy and practice levels. This is of relevance to other countries developing such legislation. The thesis extends understanding of the complexity and difficulty of moving from exclusionary to inclusionary policies and practices.

This thesis has drawn both on the literature within disability studies and the sociology of childhood to situate children more clearly within disability studies, and disabled children more centrally within the sociology of childhood so that insights and approaches from both areas are utilised within the

analysis of the social construction of children's identities in this institution for children with visual impairment.

Through bringing together the insightful contributions of key theorists in disability studies such as (Shakespeare 2006, Barnes 1999) with the theoretical paradigms and empirical work of researchers in the sociology of childhood (James 2004, Mayall 2006, Lansdown 2006), this research study has extended understanding of the social construction of identities of disabled children in institutional settings, in particular through understanding the relations between children, between children and adults – parents and staff. The children's experience of living with their disability in an institutional setting is shaped by an enculturation of socially traditional roles for disabled persons, and re-adjusted adult expectations of children and their perceived limited capacities, thus disempowering and oppressing disabled children for both being disabled, and being children. As a result, the findings of Chapter 7 (Self & Others) illustrate that the children recognise themselves as members of a specific social group, that of disabled children, and their individuality is negotiated within this group, as reflected in the findings of Chapter 5 (Exclusion versus Inclusion), and not within their family or community groups (Chapter 6 – Out of Place). Their individuality and agency is otherwise greatly restricted.

The analysis of power and control and social oppression has drawn on Foucauldian ideas of power, control and surveillance and Goffman's concepts of stigma and total institution in an analysis of a Lebanese institution for visually impaired children. Goffman's concepts of stigma and total institution were explored through the organizational ethnography and provided insights into the social construction of identity and exclusionary and inclusionary practices in relation to the use of space, the mechanisms for the children's representation and participation within the institution, and the ways in which stigma and social acceptance operated both amongst the staff and the children. The lack of participation and agency of these children was clarified at both the institutional level and within the wider society.

The analysis presented in Chapters 4 (Lebanese Policy Context) and 5 (Exclusion versus Inclusion) of the national policy and ensuing practices at the institution shows that they have created a structure of control and surveillance, which have nurtured top-down power relations between professionals and disabled people. These manifested themselves in highlighted measures of surveillance by the state (disability cards, employment quotas) and by the institution (time-space regimentation, monitoring visits, control of financial aid paperwork). This power is further decentralised in society through discriminatory attitudes and socially accepted practices towards disabled persons, which are confirmed by the parallel systems of services that have been created for them. These cumulative discrete actions represent Foucauldian power, which is defined as resulting from systems of control and surveillance that enable some actions and inhibit others. The resistance towards the implementation of the rights-based Law 220 and its failure to bring about tangible change can be seen as a direct result of the decentralisation of this power, and the absence of interventions or measures to promote Law 220 and disability rights at the level of society. Consequently, attempting to re-define disability from the top-down, from state legislation to social services and practices, has failed. This is a case study that has implications for other countries that are preparing this type of legislation in the Arab region of the Middle East and elsewhere.

These power relations were also evident within the student population, where children of high ascribed or achieved status felt entitled to restrain the actions of others, and those being restrained rarely resisted. The BAL school for residential students follows the description of a 'total institution' as defined by Goffman (1961). The institution's time-space schedule introduces another form of control, and facilitates the staff's gaze "which can neither be detected nor deflected" (Malacrida 2005): 529), through which action is enabled or restrained. Other forms of control exercised upon the children and the parents that were highlighted served to reinforce roles and weaknesses. This was evident in the dependency of parents on the institution, and the children's

restricted agency and participation. Foucault has argued that all individuals take part in these power relations, even through acts of compliance. This web of disciplinary and constraining actions has created the children's subjection within the institution and this has been reinforced by the compliance of parents.

Within a total institution, the individual's identity is restructured and redefined. For children, this started with their removal from their family and home setting. They were then oriented to actions that were considered appropriate by administration and staff at the institution. Within these interactions with the staff, the children began to form a specific outlook on their disability and their self-identity. This was reflected in the levels of ascribed status, where children recognised an assigned lower status for higher levels of visual impairment. It was seen in the 'phantom normalcy' that the educational system promoted and was later exhibited by the children themselves. The task facing the children was not only of compliance, but conformity, which emphasized their physical deviance from a norm, and which led to their self-perception of stigma that they attempted to manage to mask their difference.

The cumulative effect of these actions and systems led the children to be socialised into disabled identities. Work needs to be done to mainstream disability so that it is not viewed as deviance or a source of stigma. This can be initiated by de-institutionalising disabled children and modifying social services and systems to make measures of control and surveillance reciprocal, and share responsibility and decision-making with parents and children. Such actions would create a different web of power relations that does not oppress parents and children and allows for greater room to manoeuvre to express agency and resistance, which would ensure a constant dynamic of adjustment and change.

The concepts of power and stigma have been extended through their application to this setting, particularly in illustrating their combined influence on self-identities and marginalisation. This study

at macro and micro levels has extended understanding of the processes of change between policy and practice in the field of disability. This can be used in further research on other disabilities, as well as in comparative studies between countries in the region. Such a study can also be used to inform future social action.

In terms of the study of the social construction of children's identities, this study has illustrated the multivariate elements in social interactions, organisations and legal systems that contribute to the social construction of identities. Young children are making meaning of their lives by observing and experimenting within these realms, and the resultant responses impinge on their self-perceptions and their understanding of the social world and their place in it. This study has shown that, from a child's perspective, discriminatory attitudes manifest themselves in various ways through their daily life, reaffirming what is considered socially acceptable behaviour and roles, eventually socialising them into disabled identities. This thesis has, thus, contributed to the literature in the sociology of childhood by extending understandings of disabled children within literature, where disabled children are not central.

# APPENDIX 1 – INTERVIEW TOPIC GUIDES

## CHILDREN'S INTERVIEWS

### A. School

1. What do you like most about the school? Why?
2. What do you like least?
3. How would you go about to change it?
4. Have you ever told anyone at the school about these things that bother you?
5. Have you ever been to another school?
  - (a) What was the other school like?
  - (b) Which do you prefer?
  - (c) Why?

### B. Home

1. What do you do at home?
2. What do you like most there?
3. What do you like least?
4. Have you told anyone?
5. What is the biggest difference between home and school?
6. Are you closest to someone at home?
7. Do you go out with your family? Where?
8. Do you enjoy it? Why?

### C. Community

1. Describe your neighbourhood.
2. What do you do most there?

### D. Aspirations

1. What do you want to do when you grow up?
2. What do you want to do when you leave school?

## FAMILY INTERVIEWS

### A. Child

2. Tell me about when your child was born.
3. How did you discover the visual impairment?
4. What advice/ services were available to you?

### B. School

1. How did you make your decisions about schooling?
2. How do you contribute there? What is your relationship with the school?

### C. Family

1. How do you find that this child is different from your other children?
2. How do you deal with them when they are at home?
3. Do they affect the status quo/ running of the household?

### D. Community

1. What do your extended family members think?
2. What do your neighbours think?
3. Do you take your child out on visits?

4. Has having a child with a visual impairment strained your economic / social status?
5. Have you heard of Law 220? What do you think of it?
6. What do you know about inclusion?

E. Aspirations

1. What would you like your child to be when they grow up?

#### TEACHERS' INTERVIEWS

1. How did you become teachers?
2. How did you find/ choose to work at BAL School?
3. What do you find is different about teaching visually impaired children?
4. What input do children have in your classroom? How do they contribute?
5. How do the parents contribute?
6. What career choices do you feel the children have?
7. Why do you think there are less girls than boys in the school?
8. Have you heard of Law 220 and the movement towards inclusion? What do you think of them?
9. What do you feel is the status of blind people in our society? Do you think they are discriminated against?
10. How long have you been teaching here?
11. How does the framework allow you to contribute to institutional decisions?

#### ALUMNI INTERVIEWS

1. What do you remember most about your time at BAL School?
2. Did being a boarder affect your relationship with your family?
3. In retrospect, what would you say you learned from BAL School?

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